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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

THAI PATIENTS' EXPERIENCES OF END-STAGE RENAL DISEASE:
A PATH THROUGH AN UNKNOWN WORLD

by

Chuleeporn Piyasut

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Dissertation Committee
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Abstract

The purpose of the study was to explore how Thai end-stage renal disease (ESRD) patients manage the challenges of living with hemodialysis. The participants were Thai ESRD patients, who were receiving hemodialysis in one of the central provinces in Thailand.

A grounded theory approach was employed in this study as it focuses on social processes grounded in individual experiences of participants in the study. The participants included 30 ESRD patients, aged 26-75, who had been undergoing hemodialysis from 6 months to 12 years. Individual in-depth interviews were audio-recorded and transcribed. Data were analyzed by using Atlas.ti. Data analysis revealed “a path through an unknown world” as a central perspective that represented a holistic view of how Thai ESRD patients experienced their illness.

Participants’ experiences started by “entering the unknown world” as the context of this study. The “loss of a normal life” including sub-themes of emotional upheaval, changes in life styles, and financial insecurity” reflected causal conditions. “Tamjai: Coming to terms” served as a salient process. The strategies used to cope with their illness under their socio-cultural circumstances consisted of accepting the reality, adjusting their lifestyles, and overcoming financial struggles. “Life goes on” described the consequences of living with ESRD that included having sense of normalcy, attaining self-worth, and ongoing struggles.

These findings provide an insight into how the participants were dealing with the illness within a socio-cultural context and the limitations of the health care system in Thailand.

Dedication

This dissertation is dedicated to my parents who always give me unconditional love and support.

It is also dedicated to all participants whose collaboration made my study possible.

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This study would not be possible without the sponsorship of the Thai government who provided me with the opportunity to study at the University of San Diego. I would like to thank Ms. Umpa Kantapeng and Ms. Wipa Prasittichok who encouraged and inspired me to pursue my doctoral study. I convey a special thanks to Dr. Bulaporn Natipagon Shah who provided me support and guidance as a student in the United States. In addition, I am thankful for all of my colleagues at Boromarajonani Nursing College, Sawanpracharak who worked hard in my my absence. Thank you to all of my friends in both Thailand and the United States for their special help and support upon my request.

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Chapter I

Focus of the Study

The prevalence of end-stage renal disease (ESRD) is on the rise worldwide. According to the United States Renal Data System (USRDS), the highest prevalence of ESRD is in Japan, and Taiwan (USRDS, 2009). In the United States, the extent of the hemodialysis population had increased seven-fold from 1978 to 2008. The latest incidence rate was 346 per million population. In this population, patients aged of 45 to 64 accounted for the greatest proportion of existing patients. In 2007, the number of the new ESRD patients reached 111,000 cases. Among those patients, 54% were previously diagnosed with diabetes and one in three had ESRD caused by hypertension. Sixty-five percent of patients started their treatment with hemodialysis (USRDS, 2009).

ESRD is usually associated with several other physical health changes. ESRD patients are at risk for life-threatening complications due to chronic medical conditions and co-morbidity (USRDS, 2009; White & Grenyer, 1999). The patients need renal replacement therapies (RRT): peritoneal dialysis (PD) or continuous ambulatory peritoneal dialysis (CAPD), hemodialysis (HD), and kidney transplantation (KT), all of which are long-term and expensive treatments. Although kidney transplantation is the preferable treatment because of an improvement in life satisfaction and quality of life, the waiting list is long, and kidney donors are limited (Rudman, Gonzales & Borgida, 1995; USRDS, 2009). Moreover, many patients will never receive a transplant due to various disqualifying health factors. In 2004, only 17.9% of ESRD patients received a deceased-donor kidney transplantation within three years. Hemodialysis is the most common treatment in the United States (USRDS, 2009).

Even if the disease is treated, patients still experience restrictions due to rigid treatment regimens, diminished functional abilities, physical and treatment complications, or medication side effects. They also experience an inability to maintain employment, financial burdens, and even role conflicts in families (Ferrans & Powers, 1993; Gudex, 1995).

Renal replacement therapies affect an individual's and a country's health care costs tremendously. Medicare funding alleviates this financial burden for the patients; however, the cost of the treatment is burdensome for the federal government. The Medicare expenditure for the ESRD program in the United States was \$5.8 billion in 1991, the expense reached \$ 22.8 billion in 2001, and became \$23.9 billion in 2007(Health Care Financial Administration [HFCA], 2001; USRDS, 2009).

In Thailand, the number of ESRD patients increased dramatically within a decade. From 1997 to 2007, the incidence had increased from 10.20 to 158.92 cases per million population. This is more than a fifteen-fold increase within a decade. In 2007, the prevalence was 419.95 per million population. There were 26,457 cases, among those patients 20,641 cases were treated with hemodialysis, 1,198 cases were CAPD, and 3,618 received kidney transplantation (Praditpornsilpa, 2007).

People with prior medical conditions such as diabetes or hypertension have the highest risk of developing kidney disease. Thirty percent of Thai ESRD patients have diabetes and 18% previously were diagnosed with hypertension (Nephrology Society of Thailand, 2003). Similar trends of the primary diagnoses with diabetes and hypertension patients occurred in the United States; 72.5% ESRD resulted from primary diagnoses of diabetes and hypertension. The number of patients with ESRD is expected to increase along with the escalating Thai elderly population and an increasing prevalence of diabetes. Most ESRD patients depend on renal replacement

therapies, either hemodialysis or continuous ambulatory peritoneal dialysis to survive. The latest data indicated that a majority group of Thai ESRD patients are treated with hemodialysis. In addition to encountering the disease trajectory and mandatory and time- consuming treatments, ESRD patients also face financial problems due to its high cost. It is not surprising that many ESRD patients in Thailand encounter catastrophic financial situations (Kaseamsap, Tangcharoensathien, & Mueg, 1999; Praditpornsilpa, 2007).

Background of the Study

Thai health care providers typically gain knowledge from Western countries. It is generally believed that cultural contexts can shape the experience of patients and contribute to self-care behaviors as a health response. Western knowledge may not be applicable directly to the Thai health care setting due to many cultural differences. In addition, health care professionals may have difficulty effectively treating all chronic illness symptoms, using only a biomedical approach that ignores individualizing care regimens.

A literature review indicates that there is little information on Thai ESRD patients within a socio-cultural context. Most of the research used an instrument developed in another context and adapted for study of Thai ESRD patients. There is very little qualitative research on Thai ESRD patients who are undergoing hemodialysis. Rassmeapong (1996) conducted a qualitative study focused on stress and coping of hemodialysis patients, using a set of questions based on the theory of stress and coping by Lazarus and Folkman (1984). This study found increasing stress in patients with hemodialysis; however, the findings did not reveal how the patients managed or adapted to these situations.

Charuwanno (2005) interviewed 19 participants by using semi-structured interview consisting of guided questions based on the quality of life model proposed by Ferrans (1996).

She used content analysis to analyze the data. This study revealed seven categories among the patients undergoing hemodialysis: meaning of quality of life, health and functioning, psychological aspects, social and economic aspects, family, health care provider, and the law of karma. These studies addressed the socio-cultural context, but only from a limited number of patients in one setting.

There are very large gaps in knowledge about ESRD patients in Thailand. The type of renal replacement therapy is another issue of concern. Although HD is a major treatment for ESRD in Thailand, research in this specific area is limited. Unfortunately, there is no clear explanation of how ESRD patients on hemodialysis encounter their chronic illness. The question raised is how ESRD patients deal with disease and treatment, and how they preserve and promote physical, mental, and spiritual well-being in their lives. This knowledge will provide understanding of ESRD patients' experiences that may assist health care providers in improving holistic care or in dealing with the unique situation of Thai ESRD patients.

Line of Inquiry

The purpose of this study is to explore how Thai ESRD patients manage the challenges of living with hemodialysis. The specific lines of inquiry are:

1. What are the most concerning or challenging issues that Thai ESRD patients have faced since beginning treatment with hemodialysis?
2. How do they manage those experiences within their socio-cultural contexts?
3. What are the barriers to achieving balance or harmony in their lives?
4. What are the most helpful sources of support?

Grounded Theory

Grounded theory is a methodology for theory generation, grounded in data systematically collected and analyzed in order to describe and explain the systems, social processes, or human behaviors under study (Glaser & Strauss, 1967; Shreiber & Stern, 2001; Strauss & Corbin, 1994). This assumption drives grounded theory research by allowing the researcher to look closely at an individual's human process, interpretation of self, and their action processes that occur in the natural environment (Charmaz, 1990; Glaser & Strauss, 1967).

Philosophical Underpinnings

Grounded theory is a qualitative research approach based on the philosophic perspective of symbolic interactionism (Schreiber & Stern, 2001; Schwandt, 1994). Symbolic interactionism is one of the major theoretical perspectives in sociology. This perspective has a long intellectual history, beginning with the German sociologist and economist, Weber (1864-1920) and the American philosopher, Mead (1863-1931), both of whom emphasized the subjective meaning of human behavior, the social process, and pragmatism. Blumer proposed the term, "symbolic interactionism" as well as formulated the most prominent version of the theory. Thus, humans are defined as active, creative participants who construct their social world (Blumer, 1969).

Blumer (1969) stated that human beings are not just responding beings, people are assumed as actors regarding their roles; their actions are purposeful depending upon the meanings that people ascribe to the situations in their social world. According to Blumer (1969), three key characteristics underpinning this approach are "(a) human beings act toward things or situations on the basis of the meaning, (b) the meaning of objects derives from social interaction, and (c) this meaning is arrived through an interpretive process" (p. 3-5). Thus, people are viewed as active and creative beings that interact among groups, create meanings, interpret, and

construct actions and interactions related to those social processes in the society (Glaser & Strauss, 1967).

Rationale for Using Grounded Theory

Based on the lack of research among Thai ESRD patients who are undergoing hemodialysis, grounded theory is an appropriate choice to learn how people manage their lives in the context of existing or potential health challenges (Schreiber & Stern, 2001). Since almost all existing studies about Thai patients with ESRD have employed quantitative methods, there is limited knowledge about Thai patients' experiences with ESRD. This type of inductive inquiry has a potential to tap into the perspectives of Thai ESRD patients. The role of grounded theory allows the researcher to look closely at an individual's self-meaning and the resulting interaction processes that occur in the natural environment (Charmaz, 1990; Glaser & Strauss, 1967). The grounded theory approach is an excellent tool for understanding the processes as patients with ESRD learn to manage their chronic health conditions.

Significance of the Study

ESRD is a major health concern in Thailand due to its serious impact on individuals, families, and social systems. ESRD is usually related to several other physical health changes, and patients are at risk of various complications, some of which are life threatening. Studies have documented that ESRD patients receiving hemodialysis have lower quality of life (QOL) than healthy people. Both physiological and psychological factors faced by ESRD patients affect their QOL (Choowong, 2002; Curtin, Mapes, Petillo, & Oberley, 2002; Gudex, 1995; Kaba, et al., 2007; Maharatanaviros, 1999). In addition, the long-term treatments and costs of ESRD also affect the country as a whole (Kaseamsap, Tangcharoensathien, & Mugem, 1999). Although the major treatment of ESRD in Thailand is hemodialysis, little is known about Thai ESRD patients.

Research studies of patients' experiences of illness are very limited and primarily quantitative in nature. There is no substantive data to guide nursing practice. This study serves as an initial grounded theory study to depict the Thai ESRD patients' lives under culturally-influenced conditions. This study may provide an emergent theory to guide further research. In addition, gaining research-based knowledge of Thai ESRD patients will provide a broader understanding of how ESRD affects patients' lives, and how they responded to their chronic illness and treatment. The result of this study may contribute to the understanding of the inter-relatedness between changes in physiological, psychological, and socioeconomic conditions of ESRD patients. The findings may challenge nurses to gain insight into patients' perspectives, and to provide holistic nursing care. It also enhances Thai nurses' opportunities to base their clinical practices on research findings.

The findings from this study will assist other health care professionals to gain an understanding of Thai ESRD patients. It also will provide insight and understanding about the strategies patients use to deal with their illness within a socio-cultural context. If the health care providers gain more comprehension of the patients' perspectives, they may be able to provide more appropriate care and worthwhile interventions for improving the patients' quality of life.

Chapter II

Context of the Study

This chapter provides an overview of the contexts of patients with ESRD in Thailand. The review is divided into three major sections. The first section is a brief description of Thailand with a socio-cultural and historical overview. The second section presents an overview of ESRD conditions, treatment modalities, complications, and consequences. The last section provides a summary of research perspectives on ESRD patients in Thailand and elsewhere.

Socio-cultural and Historical Context

A Brief Description of Thailand

Thailand is situated in the middle of Southeast Asia on the Gulf of Thailand and the Andaman sea and shares borders with four countries: Laos, Myanmar, Cambodia, and Malaysia. The nation founding date was in 1238, when Thailand was known as Siam. Unlike other countries in Southeast Asia, Thailand was never been colonized. In 1939, the nation was named Thailand, which means “land of freedom.” Its size is slightly more than twice the size of Wyoming. The population of Thailand is 64,631,595 and 75% of the population is Thai. Among the non-Thai minorities, the Chinese are the largest group (14%); ethnic Malay comprise 4%, and other minorities account for 7% of the population. Thailand consists of 76 provinces with Bangkok, the capital city, located in the central part of the country. Thai is the official language. Theravada Buddhism has been adopted as the nation’s religion since the 13th century, and 90% of Thai people are Buddhist. The education system offered 12 years free basic education since 2002. The literacy rate is 92.6% (Library of Congress, 2007). Thai family structure changed from an extended family to a nuclear family. Within a decade (2000 to 2010), the average family size decreased from more than 5 to 3.1 persons per household.

In the past, agriculture was a major source of Thai national income. Gross domestic product (GDP) from agricultural products decreased from 40% in 1960 to 10% in 2002. (Sakunphanit, n.d.). In 2006, agriculture, forestry, and fishing contributed less than 10% of GDP; however, industries and exports contributed 44.9% (Library of Congress, 2007).

Perceptions and Beliefs Related to Health Behaviors in Thailand

Due to the fact that the Thai population is quite homogenous in terms of religion, Buddhism has had a strong influence on the Thai social system and their ways of life. Limanonda stated, “Buddhism is a source and medium for the culture and traditions of the Thai nation, as well as being a symbol of national unity” (1995, p. 69). Thai people have continually embraced Buddhism’s principles or dharma into their lives from birth until death. Buddhism’s principles are considered the core of Thai cultural values and beliefs, which shape people’s thinking and actions.

One of the major beliefs in Buddhism is karma. Karma is described as an immense system of causes and effects, in which everything is related and connected to one another in some way. In the Buddhist perspective, all existing things are directly or indirectly related to the flow of causes and effects. It is believed that present experiences are caused by past actions. Simultaneously, current behaviors will affect one’s life in the future. In addition, a person’s positive or negative thoughts can create good or bad karma. A person can also be affected indirectly by a relative’s good or bad actions. Consequently, thoughts, actions, as well as family’s actions can affect a person’s life. As a result, Thai people always try to do good, perpetuating loving kindness and compassion at all times, and being constrained from any bad actions.

Dharma refers to nature itself, while karma simply describes the way things behave in a cause and effect fashion (Payutto, 1993). If one does good things for oneself as well as for others, follows the Buddha's teachings and offers support to Buddhist monks, surely one will obtain good fortune and good health. Because of the belief in karma, some people may accept bad occurrences in their lives, such as sickness or crisis situations because of their actions in the past or even in previous lives. The context of merit, sin, karma, and reincarnation profoundly relate to perceptions of living and well-being for Thai people. According to the law of karma and the law of nature, it is believed that a human's life should encompass a realm of nature in which harmony with the environment, body, and mind that are inseparable (Mulder, 2000). Therefore, good health is a result of one's physical and mental balance as well as one's harmonious daily living.

In addition to Buddhist aspects, there are some other important views such as ghost and spiritual beliefs, Hinduism, and traditional beliefs that may dominate Thai perceptions of health and behaviors. Sickness can also relate to bad luck or faith as well as the anger of supernatural beings such as ghosts and spirits. On the other hand, supernatural powers provide protection, safety, and blessings for success in life. Some people also believe that a shrine or spirit house will bring good luck to the members of a Thai household. In addition, a provincial shrine located at the center of a town will protect people in that area. People offer a traditional jasmine ring to pay respects. Furthermore, according to astrological beliefs, human life is associated with the position and aspect of the moon and stars in the universe (Disayavanish & Disayavanish, 1998). Therefore, a fortuneteller uses astrology and people's dates of birth for anticipating good or bad luck and conducting a ritual to reduce and eliminate the misfortune.

Traditional Thai health perceptions may also affect patients' ways of living and their self-care. The philosophy underpinning traditional Thai health beliefs and medicine consists of four basic body elements (*thaat thang sii*): earth (*din*-solid part of the body), water (*namm*-blood and bodily secretions), wind (*lom*-respiration and circulation), and fire (*fai*-digestion and metabolism) (Molholland, 1987). The equilibrium of these components in the body affects good health and harmonious life. Imbalance, on the other hand, can cause illness. Balancing these four basic elements is the primary method for preventing and curing sickness (Disayavanish & Disayavanish, 1998).

Various kinds of foods also contain the basic body elements that promote specific body functions. Eating inappropriate amounts and types of foods can cause illness. Although perceptions about health and illness among health care providers in Thailand have been shaped by modern medicine and technology from Western countries, socio-cultural contexts and traditional beliefs still play a vital role in attitudes and health behaviors among Thai.

Traditional beliefs affect ways of life and self-care practices. For instance, people may accept unwritten herb medicine formulas to treat sickness or prevent some symptoms. Some basic traditional beliefs are used for their daily self-care, such as diluting sea salt in a glass of water as a mouthwash and chewing guava leaves to eliminate unpleasant breath. Although some of these herbs and traditional practices are scientifically proven, many of these practices remain a mystery.

Thai society is hierarchical in structure. Relationships in Thai families are marked by hierarchical structure as well. Children are taught to give respect to parents and elder generations. For example, the youngest one in the family must respect his or her older brothers and sisters. Furthermore, young people not only give respect to the older members in the family

but in society as well. In addition, gender, power, wealth, and knowledge may indirectly influence superior-inferior relationships in Thai society. Moreover, people in some occupations such as teachers, doctors, and nurses are highly respected in society. Health professionals commonly provide protection, support, benevolence, and compassion. In the meantime, the clients offer consideration, loyalty, and respect. This hierarchical social structure and the incongruent perceptions and belief of health and self-care mentioned earlier, may lead to a gap in nurse-client interaction. Nurses, as health care providers, generally play a dominant role because of a higher level of education. Due to the perception of knowledge as power, even though patients have some conflicts between their traditional beliefs and nurses' suggestions, they usually pay respect to nurses by listening quietly and not showing their resistance. Therefore, patients might not share personal approaches to the illness that contradict the suggestions of health care providers.

In summary, various traditional beliefs about health and sickness still exist in Thai culture and may influence patients' thinking and their life styles especially in dealing with chronic illnesses such as ESRD. The different views of health between nurses and patients, as well as the hierarchical social structure, can cause problems in nurse-patient relationships if the nurses are unaware, ignore, or take this nature of Thai society for granted. Other constraints and contextual factors, such as health care coverage, may also affect patients' behavior due to access to treatments and economic conditions.

Thailand Health Care Coverage

In Thailand, the health care system includes public and private providers. The ministry of public health is responsible for providing health services. There are also a rapidly expanding number of private clinics, polyclinics, and private hospitals. However, the distribution of

facilities and health personnel still is a major concern that affects equity in people's access to care. This situation may become worse if people are also facing financial difficulties. Therefore, an overview of health care coverage may be helpful in understanding the context of the study.

There are three public health insurance schemes that pay for health care services, including the Civil Servants Medical Benefit Scheme (CSMBS) and the states enterprise scheme, the Social Security Scheme (SSS), and the Universal Coverage Scheme (UCS) (Ministry of Public Health, 2004). The Civil Servants Medical Benefit Scheme (CSMBS) provides a "fee for service" program covering government employees and their dependents. This scheme also covers the aged pension population and government employees' elderly parents. This is one of the most generous schemes. ESRD patients in this scheme receive full treatment free of charge from the government hospital, and receive 2,000 baht per visit with unlimited treatments if the patients' treatment is received from a private hospital. Those who are covered by this insurance seem to face fewer financial problems.

Secondly, the Social Security Scheme (SSS) protects only workers from private companies with more than five employees. There are three co-sponsors for this system: employers, employees, and the government. This insurance covers approximately eight millions working-aged people (Praditpornsilpa, 2007). Employees with ESRD, who need dialysis treatment, are covered by the SSS, but the cost and frequency of treatments is limited to 1,500 baht and not more than twice a week. Patients have to pay the extra cost of treatment. In February 10, 2009, the government expanded the benefits for employees under the Social Security Scheme. New patients who are sick with ESRD and require renal replacement therapy will be eligible to receive 1,500 baht per visit three times a week. There are some changes for those who were under this insurance before the launch of new policy; patients would be eligible

to receive 1,000 baht per visit for not more than three times a week (Jiranantawat, 2010). This is equivalent to the previous eligibility in terms of the total amount of money of (3,000 baht/week).

Regarding the National Health Security Act (2002), the Universal Coverage Scheme (UCS) was employed as a legal basic that Thai citizen has entitlement to medical care under a public health protection scheme. Therefore, UCS provides health care coverage to all Thai citizens who are not covered by any other health protection scheme. In addition, this scheme also covers for a group of self-employed people who previously held a voluntary Health Card Scheme and indigent people of Medical Public Welfare (MPW) system. This scheme covers about 47 million people. However, the patients have to follow a hierarchy health service system that begins with a primary medical care unit. The patients are not allowed to go directly to the secondary or the tertiary facilities without referral, except for accidental or emergency situations. ESRD patients under this scheme, who started hemodialysis before October 1st, 2008 will receive 1,000 baht per visit. A new case of ESRD patient receives reimbursements for CAPD for 15,000 baht per month (Jiranantawat, 2010; Praditpornsilapa, 2007).

Overview of End-stage of Renal Disease

End-stage of renal disease is a condition that occurs when the kidneys are no longer able to excrete wastes, concentrate urine, and regulate electrolytes. It usually occurs as chronic renal failure progresses to the point where kidney function is less than 10% of baseline (Medline Plus Medical Encyclopedia, 2008). Glomerular filtration rate (GFR) is a standard measure for diagnosis of kidney failure. The National Kidney Foundation Kidney Disease Outcome Initiative (NKF-K/DOQI, 2006) provided a standard for classification of chronic kidney disease (CKD) into five stages. These five stages include: (a) kidney damage with normal or increased glomerular filtration rate (GFR) equal to or more than 90 mL/min/1.73m², (b) kidney damage

with mild decrease in GFR (60-89 mL/min/1.73m², (c) moderately decreased GFR (30-59 mL/min/1.73m², (d) severely decreased GFR (15-29 mL/min/1.73m², and (e) kidney failure with a GFR less than 15 mL/min/1.73m².

When the kidney functions is very poor or at “end stage”, with a GFR equal to or less than 15mL/min/1.73m², the blood creatinine level increases. Increased blood creatinine, a normal product of muscle metabolism and an endogenous marker of GFR, is used to monitor kidney function. The kidneys are no longer capable of maintaining a normal volume of body fluids, hormone production, and waste product excretion, which affects many body functions. When loss of kidney function reaches the point at which the kidneys fail to support the body system, renal replacement therapies are required to sustain patients’ lives.

Complications and Consequences of ESRD

Many patients with chronic kidney disease (CKD) are likely to die before developing ESRD because they are affected by an increasing level of co-morbidity (USRDS, 2005). Several complications occur with ESRD. Anemia is inevitable in ESRD because of the failure of erythropoietin production. Abnormalities in white cell and platelet functions lead to increased susceptibility to infection, easy bruising, and bleeding. Patients with ESRD are three times more likely to develop chronic heart failure than those without, and this is a common co-morbidity among ESRD patients (USRDS, 2009). Volume overload is another common cardiovascular complication for ESRD patients. In addition, lipid abnormalities contribute to vascular malfunction, anemia, and severe cardiac dysfunction due to an increase in cardiac output. Although cardiovascular death rates among ESRD patients have been lowered, mortality rates are still high (USRDS, 2009).

Hyperkalemia is the most immediately life-threatening metabolic complication of CKD and may develop suddenly when GFR is severely reduced. Anion gap acidosis results from decreased hydrogen ion excretion and may exacerbate hyperkalemia, inhibit protein anabolism, and accelerate calcium loss from bones (Nahas, 2000). Hypocalcemia is also potentially life threatening and results from loss of vitamin D and increased parathyroid hormone levels. Hyper-magnesemia also may occur. In addition to the effect of anorexia, malnutrition may occur because of acidosis and insulin resistance (Nahas, 2000). As renal failure progresses, ammonium production declines, and leads to metabolic acidosis (Levin et al. 1997). Patients with metabolic acidosis complain of breathlessness on minor exertion. Consequently, weakness and fatigue are the most common symptoms among ESRD patients. A number of studies have indicated that high levels of fatigue or tiredness are experienced (Kingllingworth & Van Den Akker, 1996; Prearungsakul, 2002). Fatigue and lack of energy significantly affected QOL for hemodialysis patients (Laupacis, 1992 as cited in McCann & Boore, 2000). Dermatologic manifestations including hyperpigmentation, xerosis, and pruritus are common and frequently lead to considerable discomfort. Pruritus is assumed to be secondary to accumulation of toxic pigments (urochromes) in the dermis.

In short, ESRD is a chronic and complex health problem in which individuals experience a broad range of symptoms or complications. Moreover, patients and health care providers have expressed different points of view regarding the severity of symptoms. Patients have been concerned about the annoying or uncomfortable symptoms associated with their daily functioning and well-being. Health care providers, on the other hand, were more concerned with the medical significance of the disease beyond interference with daily life function (Lev & Owen, 1998; Lindqvist, Carlsson, & Sjoden, 2000).

In addition to the physiological problems, psychological problems, including anxiety, are the predictable consequence of loss of health and pleasure, lack of control, dependence on others, and depression, decreasing patients' quality of life (Bihl, Ferrans, & Powers, 1998; Hagren, Pettersen, Serverinsson, Lutzen & Clyne, 2001). As a complex and chronic condition, long-term treatment relies on patients' self-management during their treatment (Curtin & Mapes, 2001). As mentioned earlier, patients and health care providers differently prioritized the severity of symptoms. Self-management regarding coping strategies and beliefs is different for each individual; therefore, it remains uncertain of how Thai ESRD patients dealing with their situations.

Treatment Modalities

There are three basic treatments for ESRD, all focused on replacing renal function: continuous peritoneal dialysis (CAPD), hemodialysis (HD), and kidney transplantation (KT). Transplantation is usually a preferred treatment option, being the most cost-effective approach; however, organ donors continue to be scarce. Since ESRD is an irreversible loss of kidney function, if transplantation is not a current option, a person with ESRD will need dialysis to survive until a donor kidney becomes available.

Hemodialysis (HD) is a process that removes concentrated molecules and excess fluid from a patient's blood through a mechanism of diffusion and ultrafiltration with the goals of maintaining volume status and treating uremic symptoms (National Institute of Diabetes Digestive and Kidney Diseases [NIDDK], 2003). Hemodialysis, functions as an artificial kidney, that allows blood flow of 400 to 500 milliliters per minute through a machine with a special filter, called "a dialyzer", that can correct fluid and electrolyte imbalances and remove toxic substances. The chemical imbalances and impurities of the blood will be corrected and the clean

blood from the machine is then returned to body circulation. Access to the circulatory system can be temporary or permanent. The connection between an artery and a vein can be made using blood vessels (an arterio-venous fistula, [AVF]) or a synthetic bridge (arterio-venous graft, [AVG]). Arterio-venous fistula is the most desirable vascular access for hemodialysis to remove and return blood to the body because rates of infection are very low and it is more durable.

Peritoneal dialysis (PD) is a process in which the peritoneal membrane serves as a filter and the peritoneal cavity acts as the reservoir for the dialysate, a special solution instilled through a catheter into the peritoneal cavity. The peritoneal membrane serves as a semi-permeable membrane that removes excess body fluid and waste products and eliminates them through the catheter. Continuous ambulatory peritoneal dialysis (CAPD) is the most popular type of peritoneal dialysis. Patients can perform CAPD by themselves, typically in four to five cycles in a 24-hour period. However, there are some long-term complications of CAPD, including peritonitis, exit site infection, and respiratory distress.

Kidney transplantation is a procedure that places a healthy kidney from one person into a recipient's body, to replace the recipient's damaged or failing organ with a working one from the donor. Organ donors can be living, or cadaveric (dead). An allograft is a transplanted organ or tissue from a genetically non-identical member of the same species. Most human tissues and organ transplants are allografts. An isograft is a subset of allograft in which organs are transplanted between identical twins. The success rates for transplant surgery have improved remarkably. This treatment is economically advantageous, costing less than long-term dialysis. Furthermore, kidney transplantation may allow the patient to return to a near normal life, but requires long-term immunosuppressive drugs. However, scarcity of organ donors is a worldwide

situation, and organ rejection is the major complication. Moreover, many patients will never receive transplantation due to various health factors that make them ineligible for transplantation

The use of each treatment modality varies among countries due to many factors, such as reimbursement, distance from dialysis centers, and availability of hemodialysis. The two major therapies for ESRD in the United States are hemodialysis and kidney transplantation. The number of hemodialysis treatments increased, while peritoneal treatments decreased.

Renal Replacement Therapy in Thailand

In Thailand, hemodialysis was first started in 1962 and became more widespread in 1986 (Kittisuksathit, Sethabut, Vanichkarn, & Kongpattanakul, 1995). In 2000, 5,963 patients were treated with hemodialysis, and the numbers increase every year (Jittinan, 2002). Currently, there are 395 hemodialysis centers across Thailand, with at least one center in each of 76 provinces. However, hemodialysis centers are not always accessible for patients who are poor or live in rural areas. Some dialysis centers are too far away, and there is a maldistribution of centers. For example, 41.9% of hemodialysis centers are located in Bangkok, the capital city. There is also a maldistribution of manpower with 64.9% of nephrologists and 70 % of renal nurses working in Bangkok and perimetropolitan areas (Nephrology Society of Thailand, 2004). Even though hemodialysis is more readily available than in the past, this treatment is very expensive. The cost of hemodialysis seems to be decreased from the past. In 2007, the mean cost of hemodialysis treatment was 1996.9 ± 289.4 baht. The cost varied due to who was the owner of the dialysis unit, which included private, government, and non-profit organizations and charity owners. However, the average cost was approximately 1,500- 2,000 baht.

CAPD was initiated in Thailand in 1982 (Kittisuksathit, Sethabut, Vanichkarn, & Kongpattanakul, 1995); however, it is less available than hemodialysis. There are fewer patients

treated with CAPD than hemodialysis and renal transplantation because the treatment is primarily available only in tertiary hospitals. The incidence of CAPD treatment per million population was 8.38 cases, while hemodialysis was 144.67 cases, and renal transplantation was 5.87 cases (Nephrology Society of Thailand, 2007). The estimated cost of CAPD treatment in Thailand is 250,000 to 310,000 baht (\$5,925 to \$7,381) per case per year (Kaseamsap, Tangcharoensathien, & Mugem, 1999).

Renal transplantation in Thailand began in 1972, eighteen years after the first successful kidney transplant in Boston in 1954. Although kidney transplantation was considered as the preferable treatment, the number of patients who receive renal transplantation was the smallest. The latest statistic regarding renal transplant was 5.83 per million population (Thai Transplant Society, 2010). In 2007, the number of ESRD patients who received renal transplantation was 370 cases (Praditpornsilpa, 2007). According to the Thai Transplant Society, the number of ESRD patients who received transplants from 2000-2009 was 2,724 cases. There are 29 transplant centers in Thailand. Currently, transplantation is limited by the supply of donor kidneys. The data on transplantation was reported from only 18 centers. The estimated cost of a kidney transplant operation was 150,000 to 200,000 baht (\$3,571 to \$4,762) per case and the cost of immuno-suppressive drugs was approximately 200,000 baht (\$4,762) in the first year (Kittisuksathit, Sethabut, Vanichkarn, & Kongpattanakul, 1995; Praditpornsilpa, 2007).

Among the three treatment modalities discussed above, hemodialysis is the major treatment of choice in Thailand. The HD: CAPD: KT treatment ratio was 144.6: 8.38: 5.87 cases per million population (Praditpornsilpa, 2007).

Research Perspectives

Thailand Research Perspectives

Although the number of Thai ESRD patients undergoing hemodialysis has increased, research on this group is quite rare. Several medical studies focus on improving medical care and improving the well-being of patients. However, most of the studies are quantitative master's theses in nursing programs. There are very few qualitative studies on ESRD patients who are undergoing hemodialysis, and most are master's theses.

Rassmeapong (1996) conducted a naturalistic study focusing on stress and coping among HD patients. She used a set of questions based on the theoretical framework of stress and coping by Lazarus and Folkman (1984). Lazarus and Folkman focused on coping and adaptation outcomes. They classified coping strategies into eight categories: (a) confrontation (b) distance, (c) self-control, (d) seeking social support, (e) accepting, (f) avoidance, (g) problem solving, and (h) positive reappraisal. Rassmeapong explored three adaptation outcomes: social functional, moral, and physical health. She interviewed 30 patients in Bangkok and found that the patients showed negative reactions to illness and treatment regimens in four major stages. In the initial stage, patients perceived abnormal symptoms prior to diagnosis; however, they did not show many negative reactions since they did not know what was happening. In the second stage, they experienced stress at the time of diagnosis. Patients experienced an increase in the intensity of their stress in the third stage, when they perceived the severity of their illness and experienced disease progression. Stress also resulted from hemodialysis treatment itself, and stress increased along with the progression of disease. For example, patients had to restrict their food and drink. Having skin changes, changes in temperament, family relationships, and losing jobs created

patients' negative reactions. This study addressed the socio-cultural context, but only in a limited way.

Rangphut (2000) conducted a study using phenomenology to explore self-care experiences of ten male and female CAPD patients who did not have peritonitis. The patients defined CAPD treatment as an important survival mechanism that also costs a large amount of money. In addition, they defined four aspects of their self-care behaviors: survival ways of living, changing their daily lifestyle, becoming a burden for their families, and treatment as a part of daily life. Health care behaviors included practicing careful disinfection procedures, monitoring food and water intake, engaging in appropriate exercise, maintaining mental health, and seeking alternative health care choices to increase well-being.

A year later, Rodschawang (2001) studied the same topic but with a different group. She examined the self-care experiences of ten male patients with chronic renal failure who had peritonitis as a result of CAPD. These subjects defined their self-care behaviors in a similar manner as those in the prior study. Their primary mission of survival led the patients to restrict their activities according to suggested procedures. They also changed their lifestyles, and treatment became part of their daily lives. They defined the primary factors that contributed to their infection as inappropriate sanitary precautions in food preparation, lax care of the environment, and improper cleansing of hands and equipment. Because of these factors, patients with peritonitis became more careful to prevent infection. They also identified many factors that supported or impeded their self-care behaviors. All participants of these two studies were government employees, who could access free care, but still experienced financial constraints. Some of them were even in debt. Financial concerns were one of the major problems of ESRD patients in many studies. Despite "free service," they had to spend their money on indirect

expenses such as food, travel, and lodging when seeking care for CAPD. One participant exhausted all of his resources and sought additional financial assistance through a foundation sponsored by the royal family.

Chokephichit (2003) explored self-care experiences of 25 patients undergoing hemodialysis. Using content analysis with Orem's theory as a framework, she developed eight categories of self-care requisites: (a) having appropriate food, (b) reducing symptoms of edema and dyspnea, (c) alleviating fatigue, (d) maintaining vascular access, (f) preventing complications from associated disease, (e) preventing deteriorated renal function, (g) reducing emotional changes, and (h) maintaining family and social relationships. Moreover, there were both external and internal factors that functioned as facilitators or barriers for self-care performances. External factors, for example, lack of family support, social support, or network, and health care resources, affected patients' self-care. Some personal traits such as interpersonal skills also influenced self-care actions.

A literature review in the Thai context indicated that, while there are some studies focusing on the situations and outcomes of ESRD patients, fewer explore the perspective experience of the ESRD patients who are undergoing hemodialysis.

Global Research Perspectives

Costello (1999) used a combined method to study 11 ESRD patients undergoing hemodialysis in the United State. Subjects completed the Concepts of Illness Protocol, the Beck Depression Inventory, and the General Adherence Scale. Costello used those three questionnaires to see the relationships among variables, then used focus group discussions about adaptation experiences among patients. Twelve nurses also attended the discussions. This study provided insight into patients' perceptions of illness as it changed during the course of the

disease. The perception of illness related to lower rates of depressive symptoms, and no statistically significant relationship between compliance and other variables was found. Patients' adaptation was placed in a broader social context such as acceptance of the disease, participating in negotiation, and assimilation and accommodation.

Delagarza (2000) studied coping and adaptation of 101 hemodialysis patients by using an attachment theoretical framework, and found that insecure attachment was a positive predictor of overall stress, poor attitude toward dialysis treatment, poor relationships with family, and negative psychological adjustment to dialysis. On the other hand, secure attachment positively related to hopefulness, perceived health competence, and perceived social support. In addition, secure attachment also related to attempting to find a positive way to deal with serious situations.

Gilbar, Or-Ham, and Plivazyk (2005) conducted a correlational study of ESRD patients in Israel. They interviewed 60 Hebrew-speaking ESRD patients who had been under treatment at least one year by using three questionnaires. The Brief Symptom Inventory (BSI) consisted of 35 items with five-point scale. The COPE scale, a 30-item Hebrew version, was used to measure coping strategies using a problem focused (PF) scale composed of six sub-scales and an emotional focused (EF) scale consisting of five sub-scales. The Mental Adjustment to Cancer scale (MAC), developed by Watson and Ramirez (1991) was translated and applied to Hebrew ESRD patients to evaluate coping with illness. The scale includes 40 items in five subscales: (a) fighting spirit, (b) helplessness/hopelessness, (c) denial (d) anxious preoccupation, and (e) fatalism. The results indicated that patients with a strong fighting spirit and good mental adjustment to disease were likely to use problem-focused strategies, while the patients who exhibited anxious preoccupation, helplessness, and fatalism seem to use emotion-focused strategies.

Kaba, et al. (2007) employed a grounded theory approach to explore problems experienced by hemodialysis patients in Greece. Twenty-three ESRD patients on hemodialysis were interviewed after a dialysis treatment. The findings revealed five key categories of their experiences: (a) problems caused by the symptoms, (b) limitation in life, (c) uncertainty, (d) dependence, and (e) changes in personality. Examining the socio-cultural context, the researcher pointed out several norms in Greek society that may contribute to positive and negative effects on ESRD patients. For instance, going out and having a meal and wine, including having a long chat with people, were important parts of Greeks' lifestyles; therefore, dietary and fluid restrictions were radical changes in patients' lives. The patients thought that they could not socialize with friends any more, simply because they loved to go to a café or tavern and have a cup of coffee or a glass of drink. Being ESRD patients, they realized that they could not drink; if they had a drink they would collapse. However, there were some positive effects, such as an extended family and social structure in Greece that provided emotional support for individuals and strong bonds among people. These also created emotional support when needed, or even resulted in compliance with treatment regimens.

Caress, Luker, and Owns (2001) conducted a cross-sectional survey of 405 patients with renal disease in two dialysis facilities in the north of England. The subjects were three groups of renal disease patients: pre-dialysis patients [patients with renal problems but not at the end-stage ($n = 155$)], dialysis patients ($n=103$), and transplant patients ($n = 147$). The number of subjects in this study covered 57.4% of the total patient population. The researchers aimed to explore the subjective meaning of their illness using Lipowkis's instrument consisting of eight categories of meaning of illness. These meaning options included challenge, value, enemy, punishment, strategy, weakness, relief, and loss. The researchers asked subjects to choose the

closest meaning of illness in terms of how they viewed their renal disease among the eight options and then explain of choices. The researchers recorded the subjects' response verbatim for content analysis. This procedure lasted approximately five minutes. The findings of this study indicated "challenge" as the most frequently selected meaning (62.5%) from these three groups of patients.

The subjects viewed the challenge option from two perspectives: positive and fatalistic aspects. The findings revealed three themes that supported the perception of a positive challenge: overcoming the illness, being normal, and all adverse life events were challenges. On the other hand, accepting and putting up with disease were two themes in the fatalistic perspective. Males more often interpreted their disease as a challenge than females. Older patients perceived their disease as fatalistic more often than younger ones. The researcher claimed that patients who selected challenge and value categories seemed to have a more positive outlook than other participants. This study provided some understanding of patients' perspectives of the meaning of their illness. Only 14 subjects declined to identify their illness from the instrument due to several reasons: they did not understand the tool, none of eight options could identify their illness, and the rest of the subjects selected more than one option. This, however, implied that maybe the subjects could not identify their meaning of illness under the limited perspectives and selected more than one.

Curtin, Mapes, Petillo, and Oberley (2002) conducted a study using semi-structured interviews of 18 long-term survivors with ESRD, who were on dialysis from 16 to 31 years. The researchers included participants by a snowball technique. The findings revealed two major adaptation processes: "restructuring self" and "restructuring illness." Restructuring self occurred through four mechanism of self-affirmation including self-preservation, self-identity, self-worth,

and self-efficacy. Restructuring of illness experiences occurred by coming to terms with four aspects of disease: risk of death or uncertain future, life constraints, intrusiveness of dialysis, and repeated setbacks. These adaptation processes made them restructure their new selves to balance and live their new lives with long-term dialysis. The researchers suggested that these two processes helped patients change to a transformational state of comprehensive active self-management. The strength of this study is that the researchers verified among the themes identified with participants and those patients with similar experiences within who chose not to participate in the study.

Curtin, Bultman, Hawkins, Walters, and Schatell (2002) conducted a cross-sectional study of 307 hemodialysis patients. The researchers developed a list of 47 symptoms from reviewing the current literature and 100 interview transcripts of patients with dialysis. In this questionnaire, subjects were asked to respond regarding how often they experienced those symptoms. The respondents reported their symptoms experiences by marking on five point Likert scale: “never” (0), “a little of the time” (1), “some of the time” (2), “most of the time” (3), “all of the time” (4). The subjects in this study experienced 22 out of 47 symptoms in the questionnaire that had mean score ≥ 1 because the score (1) meant the respondents experienced this symptom “a little time” while the score (0) referred to “never”. In other words, the respondents experienced this symptom at least once. Thus, these symptoms remained for the further analysis. However, only 17 symptoms were kept for analysis at the end.

Another instrument was the Medical Outcomes Study Short Form (MOS SF-36). This questionnaire aimed to measure eight health functional aspects: physical functioning, physical role, bodily pain, general health, vitality, emotional role, and mental health. Then the researchers

summarized the score into two components: Physical Component Summary (PCS) and Mental Component Summary (MCS).

Among the 22 symptoms reported, only 17 symptoms were significantly associated with PCS and MCS. Then the researchers classified 13 out of 17 symptoms into three categories: (a) fatigue/sleep index, (b) sexual concern index, and (c) mobility index. The other four symptoms: dry mouth, itchy skin, lack of appetite, and restless legs were identified as miscellaneous symptoms.

The researchers used Pearson correlation coefficients to see the association between three symptom indices, four miscellaneous symptoms with PCS/MCS, and the demographic data (age, gender, race, and diabetic status) with PCS/MCS. The reliabilities of three new symptom indices were acceptable, ranging from .75 to .89.

The mean PCS score was 32.9 ± 10.13 and the mean MCS score was 49.7 ± 11.09 . More than 90% of respondents reported lack of energy (mean score = 2.2), 90.5% experienced feeling tired (mean score = 2.14). Lack of energy and feeling tired were the two most common symptoms in this study. All of the three indices were significantly negative correlated with PCS ($p \leq .01$). Three of the miscellaneous symptoms: dry mouth, itchy skin, and restless legs were also negatively associated with PCS ($p \leq .01$). Age and diabetic status were correlated with PCS ($p \leq .01$). Only two symptom indices (fatigue/sleep and mobility) were significantly negatively correlated with MCS ($p \leq .01$), and all four miscellaneous symptoms were negative correlated with MCS. There was no correlation between patient characteristic and MCS. Multiple linear regressions indicated that age, diabetic status, and two symptom indices (fatigue/sleep and mobility) predicted PCS.

Curtin and Mapes (2001) conducted a cross-sectional study to measure three major variables of 372 patients on hemodialysis: self-management behaviors, knowledge of disease and treatments, and functional well-being. The researchers developed two instruments: a self-management tool and a 25-item true-false knowledge questionnaire. The self-management tool consisted of eight strategies: (a) suggestions to providers, (b) self-care during hemodialysis, (c) information seeking, (d) use of alternative therapies, (e) selective symptom management, (f) assertive self-advocacy, (g) impression management, and (h) shared responsibility in care. The overall alpha coefficients for the self-management items were acceptable, ranging from .65 to .81 with the lowest item (.65) assertive self-advocacy. Those items were categorized into two groups: cooperative/participatory and protective/proactive strategies. The functional well-being of both physical and mental functioning were measured by the SF-12 Physical Component Summary (PCS-12) and Mental Component Summary (MCS-12). The findings suggested that the patients in this study were low self-managers. The most commonly used self-management strategies were the cooperative/participatory activities of self-care during hemodialysis and shared responsibility in care. Multiple linear regressions showed self-care during hemodialysis was positively associated with physical functioning,

Hay (2005) used Roy's Adaptation Model as a theoretical framework to guide the identification of factors that predicted quality of life for 79 elderly patients with ESRD. Five self-report instruments were used: the Inventory of Functional Status-Dialysis, the Religious Coping Scale, the Life Satisfaction Index-Z, the Center for Epidemiological Studies-Depression, and the Health-related Powerlessness Scale. The findings showed that the role function mode (total functioning), and self-concept mode (depression and spiritual coping) had significant and direct effects on quality of life. The interdependence mode (powerlessness) had a significant direct

effect on quality of life and a significant indirect effect through the role function mode. Together these variables explained 68% of the variance in the quality of life of older hemodialysis patients. The strongest influence on quality of life was the role function mode. In addition, lower levels of depression and powerlessness and the use of spiritual coping along with higher levels of total functioning had positive impacts on the quality of life.

Jablonski (2007) interviewed 130 ESRD patients during a dialysis session. The subjects were asked to rate the occurrence of 11 symptoms: tiredness, itching, headaches, problems sleeping, joint pain, cramps, shortness of breath, chest pain, nausea/vomiting, abdominal pain and weakness. This tool attempted to measure the intensity (severity), timing (duration), and distress (bother) associated with symptoms. The patients rated the dimension (severity, frequency, and distress) of symptoms by reporting on a five point numeric rating scale: (a) intensity score ranging from 1 = not at all, and 5 = very severe, (b) frequency score ranging from 1 = not often to 5 = every day, (c) duration score ranging from 1 = not long to 5 = all day, and (d) distress score ranging from 1 = a little to 5 = very severe. Tiredness (77%) and problems sleeping (63%) were reported as the highest intensity symptoms experienced. Muscle weakness was reported as the most frequent (mean = 4.3, SD = 1.30) and of the longest duration (mean = 4.3, SD = 1.33). Muscle weakness also was reported as the most bothersome. The most distressing were the symptoms relating to pain or energy/vitality. Among these 11 symptoms, patients in this study reported an average of 5.67 of these symptoms. Patients who reported high scores on symptom experiences also indicated having a lower quality of life.

This chapter described various factors that affect Thai patients with ESRD. Those ESRD patients who are undergoing hemodialysis perceive and encounter their chronic conditions differently depending on personal knowledge and socio-cultural contexts such as beliefs, family

support, and social norms. In addition, ESRD itself affects various systems in the body, and the individuals' experiences of those effects are varied. The studies discussed above shed some light on the quality of life of ESRD patients undergoing hemodialysis, indicating that they experienced both physical and psychosocial problems. Several researchers reported subjective meanings of the chronic disease and the level of physical and psychosocial status by measuring them through various tools; however, there are few studies focusing on how people actually manage and live with their conditions. Most studies may not be generalized to the Thai ESRD population because of the different and diverse cultural contexts. Several qualitative studies noted that patients perceived their illness and treatments as intruding on their daily lives. There also were some findings indicating that self-care management, inner self-characteristics, family, and social support enhanced people's abilities to move toward ultimate adaptation.

There are small number of studies of the Thai ESRD population and most studies were conducted by nursing students in master's degree programs using small sample sizes. Research studies of patients' experiences of illness are very limited and primarily quantitative in nature. There is no substantive data to guide nursing practice and lack of theory to guide study based on cultural understanding.

In order to provide effective care for ESRD patients in Thailand, it is necessary to conduct research on the Thai population in order to understand them within their socio-cultural context. This may help nurses gain more understanding in this unique treatment situation. Grounded theory as a methodological approach toward Thai ESRD patients' experiences would expand understanding of this population. This understanding of patients' struggles and the management in their daily lives from their perspectives will allow nurses to provide quality care and promote a better life for them.

Chapter III

Methodology

The qualitative research method, grounded theory, is particularly relevant to this study of exploring the experiences of Thai patients with ESRD. The grounded theory method has been used to describe various data sets in areas where quantitative research has not adequately explained a phenomenon, and as a way to generate theory related to the phenomenon.

Methods

The grounded theory approach systematically gathers and analyzes data through the research process by utilizing a series of coding techniques to describe and explain systems or behaviors under the study (Glaser & Strauss, 1967; Shreiber & Stern, 2001; Strauss & Corbin, 1998). Various sources of data are collected, coded, and analyzed simultaneously until concepts and properties emerge (Glaser & Strauss, 1967). These iterative processes involve steps of theory refinement, which allow the researcher to explore both processes and actions through patients' perspectives to better understand their situations.

Theoretical sampling is an analytical process that guides data collection and continues throughout the research process in order to generate theory (Glaser & Strauss, 1967). In the beginning stages of data collection, open sampling of participants and a systematic approach are used to answer the research questions. After gaining more details from the interviews, specific questions may be revised to help the researcher compile more information. In later phases, relational or variation sampling is used to identify data, which confirms or disconfirms hypothesized relationships between categories. In the final phase of data collection, sampling is used to deliberately select events, or conditions to confirm and verify the core category, the theory as a whole, or to saturate less developed categories (Strauss & Corbin, 1990).

Two key procedures: asking questions and making comparisons throughout research processes, are crucial for guiding and directing the analyses that assist theory formulation.

Strauss and Corbin suggested that grounded theory is a “*transactional system*,” which is defined as “a system of analysis that examines actions and interaction in relationship to their conditions and consequences” (1990, p. 158-159). If the researcher understands basic social processes, symbolic interactionism, and transactional systems, these will be useful for data analysis.

The properties of a transactional system, according to Strauss and Corbin (1990, p.160-161), are made of “interactive and interrelated *level of conditions*.” The center of the system is *action/interaction*. These conditions range from the closest and most specific conditions to more general or broader features of the world. When action/interaction occurs, it results in consequences. Therefore, by nature, the transactional system refers to processes. The conditions either facilitate or limit actions; the conditions in each level may relate to the phenomenon of the study in a number of ways. For instance, they can be causal, contextual, or intervening with respect to phenomenon. In addition, the consequences resulting from action/interaction may affect or correlate to other actions in other levels or even become new conditions that create the next action/interaction. In each condition in the study, we are examining cross-sectional actions/interactions at a point in time, not over time.

Strauss and Corbin claimed that there are three purposes in utilizing this conditional matrix. First, concerning the phenomenon under study, the conditional matrix assists the researcher in being theoretically sensitive to expand all potential conditions. Second, the conditional matrix allows the researcher to be “theoretically sensitive” to possible results of people’s interaction in the society. Third, it systematically enables the researcher to identify the

range of people's experiences (conditions, actions/interactions, and consequences) with the phenomenon (1990, p. 161). The researcher employed the conditional matrix analysis process to enhance theoretical sensitivity of this study.

Data Collection

Settings

The study was conducted in Nakhonsawan province, a rural area located on the bank of the Jao Phraya river, the biggest river in Thailand. This province is located in the middle region of Thailand, 239 kilometers from the capital city of Bangkok. There were four hemodialysis facilities in the province. The participants were recruited from all of the dialysis sites: one belonged to a government hospital, two were profit/private hospitals, and the last was in a military hospital. The dialysis unit in the military hospital did not belong to the hospital; it was run by a private group that rented space.

The first dialysis unit in the tertiary-care government hospital was under the jurisdiction of the Ministry of Public Health. This hospital, the biggest hospital in Nakhonsawan, provides approximately 800 beds for in-patient care. The dialysis unit provided services Monday through Friday, from 8.00 AM to 4.00 PM with 12 hemodialysis machines. There were three nephrologists, five registered nurses, and one technical nurse.

At the dialysis units of the private hospitals, most doctors and nurses worked part-time. The dialysis units had at least one registered nurse working fulltime, and the rest were part-time employees. Due to the overflow of patients and insufficiency of open hours in the government hospital, many patients went to the two private hospitals or the military hospital. At the military hospital, the dialysis unit provides services to serve patients according to their necessities and

availability. Because of the limited dialysis capacity in this province, some participants received treatment from two dialysis units among those four.

Participants

In order to capture as many aspects of their experiences as possible, the researcher recruited participants according to the following criteria: ESRD patients who were undergoing hemodialysis in Nakhonsawan, Thailand; over 20 years of age; male or female; oriented and able to understand the Thai language; no cognitive impairment that might limit expression or communication ability at the time of interview; and willing to participate in the study. Thirty participants meeting the criteria were included in this study. All participants were Thai. The percentage of male and female participants was equal. Their ages ranged from 26 to 75 years. (mean = 46.6; SD = 15.2). The majority of participants were married. Educational background of participants was 50% elementary school level. Most of the participants lived in a rural area. Four of them lived in the other provinces, Kampanghet and Uthaitanee, where the distance from their home-town to the dialysis units was approximately 45-75 kilometers. The majority of the participants lived with families (n = 27). Even though they were single (n = 9), those participants stayed with their family after their illness was diagnosed. Only two of the single participants lived by themselves. Twelve of them still worked. Three participants experienced CAPD before hemodialysis. Two participants had previous renal transplantation that failed. Five were diabetes patients prior ESRD, 8 had hypertension, two had systemic lupus erythematosus and two had gout. The length of time on hemodialysis ranged from 6 months to 12 years. A summary of participants' characteristics is provided in Table 1.

Table 1. Characteristics of participants

Characteristics	Frequency (N=30) (%)
Age (years)	
20-30	4 (13%)
31-40	11 (37%)
41-50	4 (13%)
51-60	4 (13%)
> 60	7 (23%)
Religion	
Buddhist	30 (100%)
Educational Background	
Uneducated	3 (10%)
Elementary school (grade 1-6)	15 (50%)
Junior high school (grade 7-9)	2 (7%)
Vocational college	4 (13%)
Bachelor's degree	6 (20%)
Marital status	
Single	9 (30%)
Married	19 (63%)
Widowed	2 (7%)

Table 1. Characteristics of participants (Continued)

Characteristics	Frequency (N=30) (%)
Employment status	
Unemployed	18 (60%)
Employed	12 (40%)
Underlying disease before ESRD	
Hypertension	8 (27%)
Renal disease (Kidney stone, Nephritis)	8 (27%)
Diabetes	5 (17%)
SLE	2 (7%)
Gout	2 (7%)
Unknown	5 (17%)
Length of time on hemodialysis treatment (Years)	
< 1	2 (7%)
1-5	20 (67%)
6-10	4 (13%)
>10	10 (10%)
Type of health care benefits	
Government or states enterprise employees	16 (53%)
Social worker insurance	11 (37%)
30 baht program/None	3 (10%)

Strategies for Obtaining Participants

Before conducting the study, the researcher obtained approval of the study from the Institution Review Board (IRB) of the University of San Diego and the Hospital Board Committee where the participants were recruited. In cases where there was no formal Hospital Board Committee, the researcher obtained permission from the director of that hospital (see Appendix H).

The researcher explained the procedures and objectives of the study to the head nurse of each dialysis unit. The researcher conducted a meeting with the nursing staff in the dialysis unit to enhance their understanding of the study. With clear understanding of the study, the nurses were able to explain it to potential participants. In addition, the researcher requested assistance in obtaining qualified participants and distributing the information sheets about the study (see Appendix A). Following this, the researcher received a list of names of potential participants from the nurses of the dialysis unit.

During the beginning of the study, the researcher was at the dialysis sites to recruit eligible participants and to observe clinical settings and the social interaction among patients. The researcher approached potential participants individually and asked for permission to set up interviews. For the patients who were interested in participating, the researcher contacted each person to confirm their eligibility. Simultaneously, the researcher briefly explained the study. Once eligibility had been determined, the researcher made an arrangement to conduct an interview with each participant. The participants had the liberty to determine the locations of the interviews. The researcher confirmed the time and place of the interview by telephone one day before the interviews.

According to Straus and Corbin (1990), sampling can be approached with a series of techniques: (a) *open sampling*, (b) *relational and variational sampling*, and (c) *selective sampling*. The sampling techniques were used depending upon the stage of data collection and analysis. However, the core concept of this series of sampling approaches is theoretical sampling, which should have proven theoretical relevance to the evolving theory. In the beginning of this study, the researcher obtained participants by open sampling including on-site sampling and being a volunteer. The specific aim of this sampling was to gain the most relevant data by expanding the greatest opportunities. Thus, the researcher looked for data that might be significant with an open mind and a questioning view of the phenomenon under study.

Then relational and variational samplings were employed in order to uncover and validate the relationships between categories in terms of the paradigm: conditions, context, action/interaction, and consequences. The purposes of this sampling stage were to gain various findings in as many dimensional levels as possible in potential range.

Finally, discriminate sampling, the sampling in selective coding, was specific and deliberate as to whom or what to sample to gain necessary data. The important aims of this stage were to enhance possible opportunities to verify the relationships between categories and to fill the less developed categories. In addition, checking and testing the developing theory were the ultimate goals for grounded theory. Only the repeated findings in the data contribute to theory formation, while the negative cases indicated the variety of thoughts that were further explored.

In grounded theory, procedures of sampling and analysis happen in tandem; analysis provides guidelines for data collection. These three sampling techniques systematically proceed while constantly comparing hypotheses against the realities of data in the study.

Interview Processes

Before interviews started, the researcher reviewed the study information including aims, procedures, participant's rights, and informed consent (see Appendix D). The researcher obtained informed consent before the interviews. Data were collected using the interview guides and the demographic sheet (see Appendices B and C). The interview guide focuses on participants' thoughts, feelings, and attitudes toward diagnosis, illness course, and treatments.

The researcher conducted individual in-depth interviews to capture patients' experiences, problems and their coping with the illness across time. If the participants were more inclined to talk, the researcher preferred to let them tell their full stories in their own words. The researcher encouraged the participants to continue their sharing by adding probe questions; for example, the researcher asked, "is there anything else?", or used more penetrating questions to clarify their ideas, as needed, such as, "what do you mean by that?" The researcher let the participants guide the inquiry process by doing this. If the responses were inadequate according to the interview guides, then the researcher asked the rest of the questions. This technique allowed the researcher to gain a perspective on reality as viewed by participants. The interview guides were revised to accumulate essential data during the process of data collection.

The interviews lasted approximately 30 to 90 minutes and occurred at a place of the participant's choice, at the dialysis unit, at their homes, or another convenient place. A preferable place and time of the interview minimized fear or anxiety of the participants. Eight interviews were conducted at participants' homes. Nine of them were conducted at dialysis units while participants were on the machines. However, the privacy of a place was a major concern. In the case of interviewing during the dialysis session, the researcher conducted the interview only at

the private hospital that provided services for the patients in a separate room. The rest of the interviews were conducted in the waiting room at the hospital.

The researcher experienced interference from the social group such as family members and neighbors in a few interviews at the beginning stage. There was one interview for which the participant's husband was present during the interview. The researcher confirmed some of possible sensitive issues with this participant privately at the dialysis unit after that interview. In addition, the researcher tried to prevent such situations for the next interviews. Most interviews were one-time interviews. Only two participants were re-scheduled for a second interview in order to gain a rich expression of data. With the participants' permission, interviews were recorded using a digital-recorder. One participant declined being recorded, instead, the researcher recorded responses in a written form.

The researcher observed verbal and non-verbal reactions or behaviors through naturalistic situations, and immediately noted these reactions in field notes after individual interviews. In addition, the research also wrote operational notes that guided the processes to collect and interact with data. Moreover, personal (reflexive notes) and theoretical notes were used as parts of data analysis. Strauss and Corbin (1990) identified a qualitative researcher's requisite skills as the ability: "to step back and critically analyze situations, to recognize and avoid bias to obtain valid and reliable data, and to think abstractly" (p. 18). Prior knowledge, roles, perceptions, attitudes, or belief of the researcher may interfere with data collection and distort data interpretation. Therefore, the researcher tried to be aware of her biased perceptions and employed reflexive processes to prevent data contamination and to enhance the rigor of this study. The reflexive process reminded the researcher how she interacted with data. In addition, "a qualitative researcher requires theoretical and social sensitivity, the ability to maintain

analytical distance while at the same time drawing upon past experience and theoretical knowledge to interpret what was seen, astute powers of observation, and good interactional skills” (Strauss & Corbin, 1990, p. 18). The researcher tried to be theoretically sensitive throughout the process of interactions with participants and data. The data collection continued until data saturation had occurred and no new information was obtained.

Data Analysis

Data from the interviews was transcribed into Thai language verbatim only by the researcher. The researcher proofread the content of transcriptions by listening to the audio- tapes. Data analysis began as soon as data was collected. During the initial data collection, data analysis provided direction for theoretical sampling (Glaser & Strauss, 1967; Morse, 1994; Strauss & Corbin, 1990). A typist who signed pledge of confidentiality (see Appendix E) typed the transcriptions (Thai version) in order to help with the translation accuracy. Transcribed audio recordings were translated into English by the researcher and the accuracy of translation confirmed by a bilingual person who had also signed pledge of confidentiality (see Appendix F). Unique words or phrases from the narratives were subjected to dual translation to English by the researcher and the English language expert. Using this expertise assured a more accurate interpretation of participants’ voices. This strategy also added to the rigor of the study. Meanwhile, the researcher had used an exact Thai word in the transcriptions and provided an explanation of that word in the brackets if there is no proper word in English, in order not to distort its original meaning. Additionally, using the participant’s actual words enhances the rigor of the study as well.

Constant comparative strategies employing three coding procedures were used for data analysis. Strauss and Corbin (1990) defined open coding as “the process of breaking down,

examining, comparing, and conceptualizing data” (p. 61). The aims of open coding were to conceptualize and categorize data for further data collection. In this process, asking questions and making comparisons are two key procedures. The researcher repeatedly listened to the recorded interviews to gain insight into the narratives as a whole. Additionally, listening to the interviews, observing, and noting participants’ body language and their environments in the field notes enhanced the quality of data collection. Moreover, doing these procedures and writing her strengths or weaknesses in the reflexive notes also provided understanding to enhance the researcher’s interviewing competency. The researcher repeatedly read the transcriptions in order to capture the phenomenon as a whole, and to gain more insight into the participants’ narratives. Then the researcher analyzed data by coding line by line to construct as many categories as possible. During this process, the researcher coded and compared old and new codes to identify relevant data until categories were developed. In the meantime, the researcher explored the properties and the dimensions of each concept. Then the researcher explained the properties and the dimensions in the coding notes and provided directions for later interviews in the operational memos.

Axial coding, procedures for systematic examination of data, aims to organize and search for the connections among categories. In axial coding, the researcher addressed six characteristics of data: “conditions, phenomena, context, intervening conditions, actions/strategies, and consequences” (Strauss & Corbin, 1990, p. 158-159). Raising questions relating to these six characteristics of data helped the researcher to think about the coding categories that related to each other (Strauss & Corbin, 1990). For example, the researcher posed the question to the raw data. “What were Thai ESRD participants’ conditions or major concerns? What were strategies for dealing with those concerns? What were the consequences of the

strategies?” These questions helped the researcher to see the relationships among categories. The axial coding process also helped the researcher to gain theoretical sensitivity. Writing memos in this process assisted the researcher to identify connections among categories, and to verify associations between the categories and properties in terms of paradigms and ways to search for potential variations in properties.

Selective coding, the process of integrating and refining theory, aimed to identify the core category of the study, enhanced opportunities for verification of the story line, and demonstrated relationships among categories. Furthermore, selective coding also helped the researcher compile more substance for the less developed categories and check on the fit between the emerging theoretical framework and the realities in data (Charmaz, 2003; Strauss & Corbin, 1990; Strauss & Corbin, 1998). This coding stage represented the final step of the analysis. The operational and theoretical memos of this step further indicated specific directions of what to do and how to validate the findings and refine the theory (Strauss & Corbin, 1990).

The researcher used the Atlas.ti, a qualitative analysis computer program (student version) to organize and analyze data. The program assisted the researcher to sort out, assign, modify groups, or retrieve coding. In addition, the researcher used the program to develop diagrams during data analysis to guide conceptual thinking.

Furthermore, the researcher used theoretical memos and diagrams to assist with the analysis process. The memos reflected ideas and thoughts, while the diagrams helped to illustrate the properties, the dimensions, and inter-connections of the categories. Finally, a theoretical model was developed to present the relationships among categories that explained the phenomenon of interest. The researcher presented the findings of the study in categories, and each category was supported by quotes from participants' interviews.

In brief, the experiences of Thai ESRD patients undergoing hemodialysis were interpreted from their personal narratives, using a series of coding strategies and writing memos. The researcher identified a central category and relationships among categories. In primary data analysis, the researcher coded the transcripts independently and then arranged a discussion with her dissertation chairperson in order to confirm the analysis processes and the interpretation of data. Moreover, the researcher also worked with doctorally prepared nurses who are bilingual and experienced in qualitative research and her chairperson. This strategy was used to assist learning at the beginning stage and to attain research creditability.

Ethical Considerations

The idea of informed consent was explained to all participants before starting the interviews. The researcher individually approached all potential participants and explained the aims, procedures, and risks and benefits of the study. All information was provided in simple Thai language. A process of providing information to participants was arranged according to their literacy capabilities. If potential participants agreed to participate, they were asked to sign an informed consent (see Appendix D). The researcher provided all participants with a written consent form and a statement that the information from the interviews would be kept confidential. Signed consent forms are not culturally congruent in older generations in Thailand; therefore, the researcher gave participants an option to consent orally on digital recording. However, all participants in this study were willing to sign the consent form. Although some participants were illiterate, they were able to write their names. Pseudonyms were assigned to participants to ensure their anonymity. Data were stored in a locked location, which only the researcher could access. Information gathered from this study was not used by anyone other than the researcher. Publication or presentation of the study will not identify any individual.

Although there was no risk associated with participation in this study, some participants might have experienced small potential harms or discomforts during the process of data collection. For instance, some participants might have felt bored or uncomfortable answering some questions or experienced fatigue during the interview. In order to prevent and reduce these risks, the researcher informed the participants that they had the right to refuse to answer any questions, to stop or postpone the interview at any time, and even withdraw from the study. In addition, the participants were assured that these actions would not influence treatments or services they were receiving from their healthcare facilities. When the researcher found any harmful symptom experienced by the participants during the interviews, the researcher would stop the interviews immediately. In spite of emotionally laden moments, or experiencing some complications while under going hemodialysis during interviews, the participants persisted in continuing their stories and responding to questions. The researcher did not terminate any of the interviews prematurely, nor were participants dropped from the study due to the interview process, and the questions themselves did not provoke undue distress.

In terms of benefits, participants may not gain any direct benefits from this study. However, knowledge gained from this study could help health care providers and researchers to better understand the experiences of ESRD patients undergoing hemodialysis.

Methodological Rigor

Validity and reliability in qualitative methodology refer to different concepts than those used in quantitative research. There are four criteria for trustworthiness in qualitative research: credibility or the truth of the research, transferability or generalizability, dependability, and confirmability (Lincoln & Guba, 1985). These strategies were used to assure reliability and validity of the study.

Credibility, the degree of confidence in the truth of qualitative research findings, is established to ensure that the results of research are credible or believable. In a naturalistic study, credibility is the acceptance of the participants' points of view, or description of events, as their perspectives since the participants' stories are embedded in real-life situations (Lincoln & Guba, 1985). In this study, using an interview guide directed toward the study goal, using open-ended questions and verifying participants' responses were helpful in establishing and enhancing credibility. In addition, peer debriefing also applied. The analytical processes of series coding provides credibility for the study. The researcher read and reread the transcripts in order to immerse herself in data and discussed the codes and potential themes with her dissertation chairperson, who have extensive experience in qualitative research. This also enhanced the credibility of the study.

Transferability refers to the generalizability of the findings (Lincoln & Guba, 1985). The researcher enhanced transferability by describing the specific research contexts and the assumptions that were significant to the study. In this study, the researcher described all the details that related to participants. In addition, transferability was enhanced by theoretical sampling. In order to transfer the findings to another situation, readers will need to determine the plausibility of such a transfer.

Dependability is a view of reliability in qualitative research. Lincoln and Guba (1985) suggested that accurate and adequate documentation of changes in the setting being studied should have been identified and thoroughly described to provide dependability. To establish dependability in this study, the researcher wrote field notes and reflexive notes immediately after each interview. Completing written records immediately after interviews also contributed to

achieving reliability of information. Moreover, the researcher used field notes, operational notes, and theoretical notes as parts of constant comparative data analysis.

Confirmability is a degree to which the research findings could be confirmed or corroborated. Providing detailed procedures throughout the study for checking and rechecking the data is one of strategies for enhancing confirmability. Therefore, others are able to examine the data collection and analysis procedures and then make judgments of potential bias. A Thai doctorally prepared qualitative researcher who is an expert in grounded theory was asked to validate the researcher's interpretation of data. Furthermore, additional cross-checks also enhanced the overall quality of the study. In this study, an audit trail by members of the dissertation committee, who was a content expert and experienced in qualitative methodology, acted as an external auditor for the researcher in order to corroborate the findings. Establishing an audit trail enhanced trustworthiness of the study (Sandelowski, 1993).

Chapter IV

Findings

This chapter discusses the findings of the study. The findings revealed how Thai ESRD patients dealt with many challenges in life after they were diagnosed with ESRD. A core-perspective and sub-categories that emerged from interview data are provided in Table 2 to guide discussions.

A Path through an Unknown World

“A path through an unknown world” emerged as the salient perspective of this study that captured how participants experienced living with end-stage renal disease. A path through an unknown world starts with the context of “entering an unknown world”. It is an unknown world because participants failed to recognize the seriousness of the illness. They experienced various changes as defined as “loss of a normal life”. The process of living with their chronic illness is called “*Tamjai*: Coming to terms”. The consequences of their coping process is “Life goes on”. For further understanding, a theoretical model (Figure 1) was proposed at the end of this chapter.

Context: Entering the Unknown World

Most of the participants did not know what “End Stage Renal Disease (ESRD)” meant. The diagnosis, the treatment options, how and where they would get the treatment were unknown. They felt miserable about being sick and what was going to happen to their lives. The situation of being sick was like entering an unknown world, in which there was failure to recognize symptoms as an antecedent to serious illness. Participants experienced shock and disbelief after diagnosis.

Table 2. Categories and sub-categories that emerged from interview data

A Path through an Unknown World			
Context	Conditions	Processes	Consequences
<i>“Entering the unknown world”</i>	<i>“Loss of a normal life”</i>	<i>“Tamjai: Coming to terms”</i>	<i>“Life goes on”</i>
Shock & disbelief	Emotional upheaval	Accepting reality	A sense of normalcy
Failure to recognize serious illness	Fears	<i>Developing positive outlooks</i>	A sense of self-worth
	<i>Fear of the unknown</i>	<i>Nurturing spiritual health</i>	
	<i>Fear of dying</i>	Adjusting their lifestyles	Ongoing struggles
	<i>Fear of deprivation</i>	<i>Seeking care support</i>	
	Changes in lifestyles	<i>Adjusting dietary & fluid intake</i>	
	<i>Deteriorating health</i>	Overcoming financial struggles	
	<i>Inability to work</i>	<i>Gaining support from families and friends</i>	
	Financial insecurity	<i>Trying to apply for health insurance</i>	
		<i>Cutting down their personal and medical expenses</i>	

Shock and Disbelief

Becoming an ESRD patient was a shocking event in a participant's life. The diagnosis "End Stage Renal Failure (ESRD)" was unknown for them. One of the participants said, "I had never ever heard of this kind of disease in my life." The disease was an unknown sickness. Another participant stated, "I did not know what hemodialysis meant. I've never heard about it before. I have never seen any renal failure patients." Even the words in the disease title, "end stage", "failure", and their meanings, sent a fatal message to the patients. Therefore, when they heard the diagnosis and discovered their treatment options, it was an overwhelming situation. One participant recounted, "When I first got the disease, I was so discouraged. I thought I did not want to live anymore because there is no treatment to cure my sickness." The participant was stunned and still in shock. The severity of disease and the complexity of treatment seemed to be a death sentence for them. When one of the participants knew that she was an ESRD patient, she responded, "I cried, the definition of 'dialysis' to me meant death."

All the participants' responses generally illustrated that the diagnosis was a mystery to them. Participants with no history of underlying disease and a sudden onset of the disease would be even more surprised. This was one of the expressions, "I could not believe that I was sick. I had always been a healthy person. I've never gotten sick before... I felt suddenly tired. I was so weak. Usually, I was a strong person. At the time I was sick, even a 10 step walk could kill me." These statements showed that his condition was an acute onset, and he experienced deadly symptoms. Many of the participants experienced a severe, acute condition considering as a life-threatening situation. Several of them had to start hemodialysis on the first day that they went to see the doctor.

In response to a question related to past illness, one participant replied, “Actually, I had no illness, but when I went to the hospital and the doctor told me that I had end stage renal failure.” His disease progression was relatively fast. Once he felt something was wrong and sought medical care, his condition had already become so severe that it required an immediate treatment. Another participant who was young and believed that he was physically fit also experienced a sudden onset of symptoms and becoming seriously ill within a couple days. He recounted, “I was usually doing well. I worked and did everything normally. I did not like to see the doctor and I never got so sick that I needed to be seen by the doctor, ever.” From the conversation, the participant perceived that because he was young and healthy, minor health problems might not lead to a very serious disease. Participants were usually unaware of their trivial abnormal symptoms if they were young and healthy

On the other hand, participants who had other illness prior to ESRD also experienced the same feeling, although their illness had progressed from their underlying disease. One participant with diabetes recounted, “One day, the doctor checked my blood and found that I had a renal problem because I had diabetes for a long time (more than 10 years). He told me that I had renal failure and it was getting worse little by little. Finally, he told me that I had to be treated from another hospital.” Another participant who had been diagnosed with hypertension believed that he was living healthy because he did not know any possible symptoms and complications of his underlying disease. He expressed, “I was always a healthy person. I had never gotten sick before then. I knew that I had hypertension, but my blood pressure was not very high.” Since the participants experienced minor symptoms of their illness, they believed they were healthy. Therefore, getting sick with ESRD was a shock for them.

Having ESRD had directly affected participants' feeling as mentioned above, which was a primary theme that they experienced as a context of a path through an unknown world. In addition, most of the participants did not know what a leading cause of their illness was. Although some participants had had a chronic illness prior to renal failure, they also did not know what to expect from their symptoms. They did not know that their underlying illness could cause any other diseases. They were unable to anticipate its complications that might lead to ESRD.

Failure to Recognize Serious Illness

Many participants' stories illustrated a sense that they failed to recognize their symptoms as serious. The failure to recognize was a prominent antecedent due to insufficient basic knowledge of health, ability to detect any abnormal symptoms, and a specific knowledge of their current disease. One of the participants said, "I did not know anything about renal failure. It was like I was blind. Nobody in the whole village experienced this problem. My relatives had never known about this disease." Another participant recounted, "I had kidney stones since I was 21-22 years old. I had several surgeries... Later, one of my kidneys was dysfunctional, so I had to remove one of them... I think water has something to do with my kidney disease. The surgery took place in left and right kidney until it was failure." This participant experienced recurrent kidney stones and had operations several times. Finally, he learned that his illness might be associated with renal failure after he had only one kidney left. He was able to be with one kidney for 10 years before he became an ESRD patient. The participants did not have knowledge regarding their illness in order to prevent entering end stage renal failure.

Participants were unable to recognize initial symptoms that might indicate a serious illness. Their trivial symptoms might have progressed before receiving proper medical care.

In an excerpt from one participant's statements, "I realized that I periodically had swollen eyelids when I woke up and it was gone in a couple hours. This had happened for almost ten years. I never thought that was a health problem. I thought it was from my long sleeping at night." For many years, this participant had never paid attention to the eyelids swelling at all. The swollen eyelids seemed to be a normal occurrence for her. According to her perception, her long hours of sleeping was the cause of the swelling. She continued telling her story of how she failed to recognize the illness:

"I did not have backache like others, but I have had swollen feet, I thought it was normal because it happened when I had been driving to another city. I remembered that it had happened twice. My swollen feet were so big that I could not put my shoes on. I thought that was a result of sitting in the car for too long. In addition to having swollen feet, I also had bloody urination once, but I did not pay any attention either. It was just only a little amount of bloody urine, and then it was gone. I also had a fever and chills at that time, but it lasted less than an hour."

Her presupposition of renal disease was only associated with having back pain. Without back pain, she thought her experiences of having swollen feet happened because of sitting in the car for a long drive. She did not doubt that there were other possible causes of her swollen eyelids and feet. She realized and was able to connect her signs and symptoms with her ESRD later. However, it was too late; she was in renal failure and required dialysis. Another narrative excerpt below also indicated the insufficiency of basic knowledge of health that led to being severely ill:

"I could not see very well, and I had dizziness. I had blurred vision. My health was so bad at that time. When I went to the hospital, the doctor thought I might have renal failure. I had an ultrasonic test for confirmation. The result was I needed to be on hemodialysis... I thought it was eye problems; I went to see an ophthalmologist. The doctor found out that I had high blood pressure. I had no idea that I had been sick with hypertension and renal disease... It was only two days after I learned that I had ESRD, the third day at the hospital I had to start hemodialysis."

Furthermore, having abnormal symptoms relating to health problems or everyday activities could create a misunderstanding for patients. One participant recalled, “I had severe back pain, but I thought it was related to my hard working. I used to work very hard to earn my living by loading and unloading rice sacs. My back hurt badly, I hardly moved. I did not know this symptom might be associated with kidney disease. I took pain pills, and that helped me sometimes.” These situations delayed further seeking proper medical attention, and led to late detection of his disease. Therefore, he finally became an ESRD patient.

Some of the participants had a chronic disease prior to the renal failure such as, diabetes, hypertension, systemic lupus erythematosus, or gout for quite some time. They seemed to recognize that they had experienced health issues, but they did not consider their seriousness. Although these participants had lived with symptoms of their chronic illness for years, they did not have any idea of potential complications. One participant stated, “I knew that I had hypertension, but my blood pressure was not very high... I knew that I had high blood pressure about a year or two, and the doctor gave me medicines. I took the medicine and then I stopped it because I had no symptoms. I never thought it would cause this severe sickness.” This statement sheds some light on the lack of knowledge regarding the underlying disease. He thought his blood pressure would not do any harm to him since it was not very high. The lack of knowledge and having no detectable symptoms caused this participant to assume he was fine. Therefore, there was no further action on his hypertension, and he even ignored his medical prescription. Another excerpt below also indicated that the participant lacked knowledge of his specific disease, “I had only hypertension... I did not have any symptoms; I had no headache, vertigo, or dizziness. I did not take medicine regularly. I felt like I was normal, I did not continue my medicines.” His perception of being ill should have included physical symptoms. If he had

problems regarding hypertension, he would have had at least a visible symptom. Since he did not, he ignored taking the medicine. Therefore, lack of knowledge about hypertension and its complications contributed to a late diagnosis and treatment. By the time, participants sought medical care many of them were already in renal failure.

Conditions: Loss of a Normal Life

The kidney is a vital organ in the human body, and when affected by end stage renal disease it leads to deteriorating health and physical function. Therefore, participants experienced various signs and symptoms that interrupted their daily activities or even created life-threatening conditions. After being sick, participants' lives changed in many ways; one participant realized that his life would never be the same. Loss of a normal life captured conditions, which occurred and affected participants in this study. Other conditions, such as: emotional upheaval, fear, changes in lifestyle, and financial insecurity, were major components that created this loss of a normal life.

Emotional Upheaval

Having an incurable disease was an unexpected situation that participants never thought would happen to them. Participants thought being sick as ESRD patients was the end of their world. In addition to shocking news and a sense of disbelief, the disease was severe and life threatening and created emotional distress. Their emotions ranged from guilt, denial, to severe depression. One of the participants felt guilty about what he had done in the past, he said, "I should have had the physical exam earlier... I think if I had been checked-up earlier, I would not get such a severe sickness like this." One participant demonstrated his denial passively: "I didn't want to obtain any information. I was hopeless and stressed. I did not care how the doctor would treat me. I paid no attention to anything and did not search for any information about my

sickness.” This participant felt that there was no way out of the problem. He had no motivation to do anything. Although participants might have gone through the initial stage of shock, some continued to feel that being ill was unacceptable. One participant who has been treated around five years expressed, “I cried very often, but I did not let people see me cry. I could not accept the fact that I was sick.” In addition, changes in lifestyle, such as the inability to work, intensified emotional upheaval. As one of them said, “When I couldn’t work, it was irritating because I used to do everything myself. I feel discouraged.”

Having an incurable disease directly affected participants’ emotions, they reported that they were more easily irritated. In addition, participants realized that they coped with their emotions differently than they used to. One of the participants recounted:

“I got tempered easily with my wife and my children, whatever they did was wrong for me... For example, I wanted to eat something like noodles, when they did not bring it fast enough or the taste of the food was not as good as I expected. I got really mad, and I threw everything.”

Moreover, many participants noticed that their emotion upheaval was associated with high waste products in their blood test. They had difficulty to control their reactions as they previously had. One participant said:

“I know I was stressed and irritated especially on the day before having dialysis. It seemed what they (other people) did was all wrong, if they did not do it my way. Sometimes, I directly expressed my feelings. Actually, I did not want to say anything impolite, or hurt their feeling, but I could not help myself on that. I knew the cause was my emotion.

Some participants experienced a mild depression while others experienced a more severe depression that reoccurred periodically. One of the participants indicated that his worry caused him a psychosomatic symptom that needed medical attention. He was in a deep sorrow, he said, “I could not go to sleep at all. I needed sleeping pills to put me to sleep.” Another participant, who had similar experience, recounted, “I was worried. I could not concentrate on doing

anything. I always had scattered thoughts. It was hard to be calm. I thought about everything.” Another participant who admitted that he was depressed remarked, “I isolated myself in my office or in my house only...I was depressed, I did not want to talk with anyone. I did not start any conversations.” Some participants limited their daily routine to things that contributed only to survival. They did not want to talk to anybody or to do anything. They felt lonely and desperate. In addition, the illness also had an impact on participants’ self-images. One participant recounted, “Sometimes, I thought I was not like other mothers. I felt sorry for my kids. Since I got sick, I did not feel like dressing up at all.” Experiencing many physical and emotional struggles, a few of them even expressed a wish to die. One participant stated, “I thought about committing suicide by having drug overdose.”

Fear

Fear was a typical feeling that the participants in this study mostly experienced after hearing the bad news. The sickness itself generally created fears. In this study, the participants repeatedly used the exact word “fear” as well as implied words that were associated with fear. They were afraid of many things that were happening at that moment and what would happen in their future. One participant asserted, “I did not know what was going to become of my life.” Some participants were able to specify what they were afraid of. On the other hand, many of them were not. Although there were various kinds of fears identified in this study, it was clear that most participants experienced “fear of the unknown,” “fear of dying,” and “fear of deprivation from family and loved ones.”

Fear of the unknown. The mystery of the disease created a fear of the unknown because it was a leading cause of uncertainty and worry of what would happen in the participants’ lives. They felt as if they were blind or walking in the dark and unable to find their way. Fear of the

unknown started even prior to the diagnosis. One participant who did not know what to expect and denied the possibility of serious illness stated, “The worst time for me was during a period of further testing at the provincial hospital because I had no idea of what was going on. It was doubtful that I might have renal failure. I thought it could be something else.” In this case, a long period of staying at the hospital and, further investigation for diagnosis increased her anxiety.

Another woman experienced a similar feeling before knowing that she was an ESRD patient. She stated, “At that time, I was doubtful about my condition. Maybe I had bladder cancer.” She thought about the cancer, which was a deadly disease to her knowledge. She also articulated her symptoms as well as the treatments associated with a serious disease. Her feeling of fear was very strong. She continued, “The doctor had to do so many things to me. It might be a severe sickness. I cried and did not let the doctor do the procedure.” She assumed that going through many procedures meant she had a serious disease as well. She thought that she had the worst sickness that she knew, such as cancer. The fear continued to haunt her although this participant lived with ESRD for five years.

When she started feeling numb in her legs, this also intensified her fear because of the unknown complications. She recounted, “I was scared. I worried about having paralysis in the future.” This statement clearly demonstrated the fear of her future. Another participant’s fears were mixed but still contained a sense of fear of the unknown. He said, “I was afraid of everything. I thought that my sickness could not be cured. I was also afraid of death. I was afraid of going to the hospital, having pain, and everything. I had never been admitted to the hospital in my life.”

There were several reasons that contributed to fear of the unknown. For example, not knowing about the disease, including its treatment options, primarily caused fear. Some

participants recounted their feelings: “I was very afraid; I had no idea of any kidney failure before... I had never ever heard of this type of disease.” Another person said, “I did not know any kind of procedures that I would go through during the treatments.” Another expression of a young man demonstrated his constant fear from the beginning until he started the treatment. He said, “I never knew about this before so I was confused. I had no idea what the doctor would do. At the beginning, he just stabbed and put a long tube into my neck. I was very scared. I had never seen or experienced anything like this before.” The sudden symptoms made him afraid and the procedure of treatment intensified his fear.

The severe conditions and the hemodialysis itself were a part of the unknown that also created more fears. One of the participants expressed, “I was afraid of my condition. After I knew for sure that I had to be treated, I was so worried. It was stressful.” One participant had a sudden onset of severe symptoms. He passed out once before being taken to the hospital and being diagnosed. He stated, “I was scared and thought that I wouldn’t make it, because I was unconscious, and I couldn’t breathe. That was what I remembered.” Fear of the treatment was also common. One of the women recounted her fear of having the first hemodialysis, “I was so scared. My heart pounded so fast.” Another woman recalled, “The first time, I felt like I was floating.” This woman explained more about her feeling of floating, which was like she was going to die.

Fear of dying. The feelings of fears fluctuated but the ultimate fear was the fear of dying. The participants directly and indirectly expressed their fear of death. One participant concisely expressed, “I also cried, the definition of ‘dialysis’ to me was death.” It was a clear statement. Another participant recounted, “I thought I was already 50% dead. I felt discouraged. My tears fell down.” As I mentioned earlier, the unknown activated fear, however, knowing about the

disease also created fear. If participants had seen the severity of the disease that ESRD patients suffered and died, this would add even more fear for this participant. One participant had a direct experience of seeing his relative die because of the disease. He expressed his fear:

“I thought I had to die very soon for sure. I had one of my cousins, who got sick because of renal failure. He lived only a few months after the diagnosis; he did not get hemodialysis treatment though. I imagined I would die sooner like him. I felt sad.”

Some participants talked about the fear of dying many times within a short conversation. These were some examples: “I thought I would die sooner... I thought I would die very soon. Yes, I felt I would die in the near future.” The fear of dying kept coming up in her mind. Another participant repeatedly said, “However, I always warned my son that I might not be able to live long. I do not know when I will die... Actually, I still could not accept death... I worried that I might die.” Her fear of dying was pervasive in her conversation. Whatever the topic of the conversation was, she would say something that related to her fears. She kept bringing up the fear of death: “How long am I going to live? I am still afraid of dying. I cannot get rid of this feeling.” The fear of dying kept haunting her periodically from the beginning until the time of my interview that was five years after diagnosis. The individuals’ fear of dying was related to being unable to fulfill their dreams and ambitions, raising their children, retirement, and just living a “normal” life.

Fear of deprivation from family and loved ones. The thought of being away from families and loved ones was associated with the fear of dying. One of the participants specified her fear, “Death or deprivation from my family and my husband.” It was hard to discuss the issue of dying and being away from families separately. These feelings were interwoven and blended. Another excerpt below illustrated the fear of dying and being unable to care for the family:

“I wished to be alive. I asked whoever helped me please. I begged not to die to everyone. I thought about the monks and my parents who died a long time ago. I was

worried, how my wife would bring up our son alone. He was still a baby. If I died, what would happen to my family? This thought repeatedly came up in my mind all the time. So I kept begging for life. If I did not die, I was willing to be a monk at least seven days.”

The fear of death from this excerpt not only was associated with his dying but also illustrated anxieties for his family’s future. Death would affect various things in his life. Another participant had a relative who died of ESRD; he had imagined himself in this situation. He recounted, “It was a scary disease to me. I was afraid of being sick like him. I thought if I got the same sickness as he did how I would manage my family’s life. I had never thought that my fear would become true, you know.” Although the participant was single, she still worried about her nieces and nephews. She wished to see them grown up, “I did not have my own kids, but I love my nieces. Was I going to die? I questioned. I was so scared. I wished to see them grown up too.”

Changes in lifestyles

Changes in lifestyles were common conditions that happened after being an ESRD patient because participants had to compromise with the illness for survival. One of the participants, who had many unhealthy habits, such as drinking a lot of coffee during the day, smoking at least two packs of cigarettes, and drinking three bottles of beer before bed-time stopped everything after his sickness. He said, “I didn’t drink beverages that were no good for my health... I stopped it because if I did not, I would have died.” The ESRD forced him to stop all of his unhealthy routines immediately. Otherwise, he might have already died at the very beginning of his illness. Moreover, he was concerned about his health more than he was in the past. He said, “Now, I want my body to be with me longer. I do not want any stress...I noticed that whenever I had a lot of stress, I felt tight in my chest. My stress was about financial

problems. I thought about it repeatedly. I have to let it go, but it was very hard.” Since his health still deteriorated, he tried to be easy on himself in order to compromise with his illness.

Changes in lifestyles occurred on an individual basis. One of the participants, who used to be very independent and loved traveling, was very weak and fainted frequently. He recounted, “I could not go anywhere. My children were afraid that I might faint when driving. They took away my car keys. I felt like I was trapped in my own house.” Due to his unstable health condition, it was risky to live his life the way he used to.

The loss of physical abilities was an obvious and major change due to the illness. Therefore, many participants were not capable of doing what they liked to do. One participant said, “I was a sport man, I could play all kinds of sports.” In contrast, these days after the sickness, he said, “I played nothing.” Physical changes also affected family relationships. One of the participants said, “The disease made my sex life slow down. I mean my feelings were the same, but physically I was not ready for that. I told my wife straightforward.” Physical functioning was one of the concerns of relationships and it created a potential problem in the future as well. As one of the participants recounted, “Since I have to do the hemodialysis like this, I don’t know how long she will stay with me. Maybe we might not make it... We are dating now; I am not sure about the future.” Because his illness required long-term dialysis, he thought that he was not normal. Having this idea in his mind therefore, he worried about his long-term relationship with his girlfriend.

However, the changes in lifestyles were not all negative. The difficulty of situations in life made the participants give themselves reasons and find ways to manage their lives differently. One participant said, “There were so many things that had changed in my life. For example, in the past I was afraid of injections. After I received many injections and took many

medicines each day, I got used to it. Now I am fine when having injections.” He admitted that his fear of going to the hospital and being tested, prior to the diagnosis, made his illness become worse. He did not go to the hospital for any check-ups in spite of warnings by the doctor. He considered his change after his illness to be a good thing in his life.

There was another positive change from the participant’s perspective. One participant who still worked as a government employee also had to take care of her ESRD mom; they both were on hemodialysis three times a week. She recounted, “I think I could adapt very well. I always get up early in the morning. I do house work such as cooking, cleaning, and washing clothes. I can do everything just like normal... I think the tough situation made me strong.” Twice a week, she had to drop her mother off at the dialysis unit before going to work and pick her up during her lunch break. However, the third session of the week on Sunday afternoon they both went to the same hemodialysis unit at a private hospital. She considered herself a well-adapted person. She was proud of what she had done for taking care of her sick mother and herself. She asserted, “It was clear that my time management is better because I have to be more concerned about planning. I must determine what to do and when to finish the tasks. I planned for everything. I think I can manage things well. Everybody was amazed on how well I could do it.”

Changes that affected participants’ lives could be both positive and negative. However, deteriorating health mostly became a primary cause of other problems.

Deteriorating health. The physical condition of ESRD patients was also a major struggle due to their deteriorating health. One of participant recounted on his health status, “I had joint pains, dizziness, headache, and fever. I easily got sick. It was like I always had a health problem. There was one thing after another, I am not normal. Sometimes, it was so painful and I could not

even walk.” However, symptoms experienced by participants varied in wide ranges in terms of symptoms and severity. One might complain of various symptoms. As one participant said, “I had experienced a lot of suffering since I got sick.” On the other hand, one of them reported, “I was very tired. I wanted to sleep all the time... I slept all day.” Being tired was the only problem that kept bothering him at all times.

In addition to the renal failure, many participants had another underlying disease prior to ESRD. Therefore, deteriorating health was an unavoidable condition among several ESRD patients. Participants’ lives changed because of the sickness in many ways. One of the participants who considered himself relatively healthy and strong said, “I was a strong person. I was a sportsman; I could play all kinds of sports. I never thought of getting a severe sickness like this.” Due to his sickness, he no longer played sports. His life style had changed. He was not able to be an out-going person anymore. Another participant recounted, “In the past, I loved going to the seashore on my vacations. I would run into the water, but these days I needed somebody to be by my side and walk along with me. It was not fun anymore.” The excerpts above were explicit examples that deteriorating health directly affected individual’s lifestyle. As one participant stated, “Life was no longer the same.” That was how the participants exactly described their situation after having end-stage renal disease.

Deteriorating health was often a primary factor that led to other changes in participants’ lives. Experiences of ESRD participants due to deteriorating health, ranging from discomfort to life threatening, diminished their ability, both directly and indirectly, to work.

Inability to work. Chronic illness conditions, continuous treatments, and rigid prescribed regimens for ESRD caused the participants to be unable to work. Even doing nothing, some participants still experienced health problems. One participant expressed, “I did not work.

Nevertheless, I was sick very often. If I have to work, I do not know what would happen. Working seemed to be impossible.” Many participants quit or changed their jobs owing to various factors: physical weakness, conflicting work and dialysis schedules, or even changed locale to access care. One participant asserted, “I quit my job since I knew I had renal failure.” She stopped working at a souvenir and snack store because she could not perform her physical functions. For instance, she was easily tired, could not lift anything heavy, or re-shelve merchandize whenever customers bought goods from the store. Therefore, she gave up on her work. One of the farmer participants, who considered himself a hard-working person, could not work as he used to do. He had a busy working routine for more than 20 years, working in his rice field, and selling fresh vegetables and fruits at a local market early in the morning. The ESRD caused this participant to give up his work because he could no longer function well. After he got sick, he was weak. His feeling on the change in his daily life was remarkable. He said, “Whenever I saw the fruits in my garden, I felt bad that I could not sell them anymore...I really want to do trading again. I miss doing it.” His sickness took away his routines. In addition to his physical function, this participant also needed to get treatments three times a week. In order to do so, he had to stay with his daughter the night before the dialysis schedule. He recounted, “I went back and forth between two houses either staying with my wife or with my daughter. I sometimes stayed with my daughter when I had to go to the dialysis unit. I had to connect three buses to get there.” His life changed, and he could not work anymore. Five hours of the dialysis session, three times a week, took away his strength and the time he used to enjoy.

Unlike the farmer, many participants tried to preserve their work schedule as much as they could. Many of the participants set their dialysis schedules at night or on the weekend at private hospitals because their working hours were eight hours a day and five to six days a week.

Despite paying more money and traveling long distances to access the hemodialysis, the participants could continue their work. This strategy worked fine for participants who were quite educated and had stable jobs. In contrast, this was impossible for laborers who had unstable jobs and got minimum wage. Participants who were unskilled laborers had to stop working because of their deteriorated health. As one of the participants said, “It was not as convenient as before. I had to be careful. If I did something wrong, it could cause trouble. I tried not to lift anything heavy, I slowed down everything, I could not work that much.”

Many participants stopped their former jobs and tried to do something else because their physical condition did not allow them to work the same job they used to. Some of the participants were lucky about finding a new job. One participant was a digging-truck driver before he got sick. When he got sick, he had to move and stayed at his mother-in-law’s house to access treatment. Therefore, he had to quit his job. However, when his condition was better he tried to find a new part-time job that was flexible for him, so he could work and get treatment too. The only job he could get was unstable. He worked and got paid on a day-by-day basis, he said, “A job like this was a temporary one. I had to take a break often- twice a week.” Therefore, I could not apply for any regular work as others did.” His employer let the participant work as a part-time driver because he felt sorry for him and tried to help as much as he could. However, the participant could not work as much as he really wanted to. A conflicting dialysis schedule and working time was one of the factors that contributed to his inability to work full time. Moreover, he had hemodialysis only twice a week on Monday and Thursday; therefore, during a longer period of the cycle he experienced uneasiness. He recounted, “For example, I had the hemodialysis on Thursday. The next three days my body began to swell. The day before the next dialysis session of the longer cycles, I felt tight in my chest and tired but I could do some work.

Sometimes, before having the dialysis, I was weak and I could not work.” Deteriorating health directly caused the participants to be unable to work. The combination of costly treatment and inability to work lead a domino effect and financial dilemmas.

Financial Insecurity

A major challenge that the participants expressed was financial concern. The challenge was how to come up with the money to pay for the costly treatment, which was regularly required, and how to maintain a family’s income, if the head of family was unable to work. In addition, access to treatment intensified financial dilemmas if the participant had no health insurance and lived in a rural area that was far away from the hospital. Therefore, finance was a common challenge for all, even those with insurance.

One participant said, “I did not get any financial support from the government or any kind of health insurance. I had to pay all by myself.” Even participants who had social health insurance encountered similar situations. One of the participants complained, “I also had financial problems because the social insurance did not cover the hemodialysis. I paid a lot of money for my treatments. It was too much for me... I do not know how long I could continue the hemodialysis, the money is important.”

Some participants became burdens to their families. As one of the participants said, “My father got a million baht loan from his working corporation. However, it did not even last for a year.” The participant spent a lot of money on her illness even before the hemodialysis. She said that she spent a big bulk of 30,000 baht just for her vascular access. Another participant who was undergoing hemodialysis for two years, recounted:

“My mother had already taken out a half of our wooden house and sold the wood to pay for my treatment. My father is old and can hardly work in the field. I don't know how long my family would be able to afford my treatment. I feel very sad that they were in trouble because of my illness.”

This participant became physically, emotionally, and financially dependent to her family. Her parents were responsible for her treatment and her daily cost of living because she was unable to work. Even in her daily living, she still needed help from her mother. Her mother rented a room close to the hospital for her to stay in. She bought food, put it in the refrigerator, and came to visit and checked on her periodically.

Although in some cases, finances seemed to be less difficult, they still were a major concern. For example, a man who received total reimbursements for his treatments and underwent hemodialysis for seven years also commented on his financial situations. He said, “My finances, all our expenses were tight. I tried very hard to balance my income and the expenses. It was difficult to get a loan from someone in case of an emergency need.”

As can be seen from these participants’ stories, financial insecurity was a major problem that most participants had to deal with. There were many underlying factors intensifying this problem, such as being unable to work, expensive health care costs, and rising debt. However, participants learned that the treatment was necessary. All of them had to find ways to walk through this unknown world.

Process: Tamjai: Coming to Terms

Since participants entered a path through the unknown world, they experienced physical discomfort, malfunction, even life threatening situations, and loss of a normal life. These were causes of suffering in their life, but it had already happened. It was their life. Participants came to terms and embraced their illness with an expression in Thai “*Tamjai*” (coming to terms). *Tamjai* was often used by the participants in this study that referred to accepting an unexpected or difficult situation in life. Using the term *Tamjai* has the meaning of acceptance and living within that ongoing situation. Many participants expressed realistic outlooks on their situation that

reflected *Tamjai*: coming to terms such as, “Whatever will happen, it will happen,” “Let it go, let it be,” “It is going to be this way,” and “It is the law of karma.” These were sentences and phrases, that participants always kept in their minds. The meaning of these phrases reminded them to accept what had happened, and what is going to happen to their lives with less frustration. *Kerd* (birth), *kaa* (being old), *jeb* (being sick), and *tai* (death) are normal in life, these religious beliefs facilitated participants acceptance of the reality in life. After they learned and truly understood this reality, they were able to live with ease. Acceptance of death is derived from religious beliefs. Death is an ultimate and definitely unavoidable destination of life. Buddhism, therefore, is familiar with a typical phrase “everybody dies (ทำใจทุกคนเกิดมามีต้องตาย).”

Many of the participants experienced serious life-threatening symptoms, and even received the hemodialysis treatment at the very first day of their search for medical care. Therefore, those participants who were exposed to severe or life threatening situations, realized that the hemodialysis would be an essential part of their lives. One participant recounted his experience in starting dialysis immediately. He said, “I was sent to the emergency room. I coughed. I could not breathe, sit, or lie down. I had nausea and vomiting too. I was suffering; I had pleural effusion. I was still conscious, but I felt as if I was about to die. I also saw that doctors and nurses were very busy helping me.”

This participant was amazed by how hemodialysis saved his life. He appreciated the approach of healthcare personnel and the advantage of having dialysis machines. He stated, “If there was no dialysis machine, what could I do with my life? I had never known that there was a machine functioning as the kidney before, until I was sick myself. It is a magic machine. I survived and was better after the treatments.” After participants directly experienced sickness severity, they decided to obtain the treatment regimen, as this was the only way for them to

continue living. *Tamjai*: coming to terms was a salient perspective shown as a starting point of how participants dealt with their illness and struggles. Despite the fact that their life would never be the same, they were able to see the other side of the coin under their struggling situations.

After they came to terms with being ill, they determined that they would lead meaningful lives. They had to take charge of their illness. Participants somehow demonstrated that they tried many ways to minimize and overcome their struggles. Accepting reality, adjusting lifestyles, and overcoming financial insecurity were sub-categories of the process of a path through an unknown world.

Accepting Reality

Accepting reality was one of the factors that facilitated participants' move forward. The participants' outlook was an important key to how they managed their lives. Many participants illustrated how their state of mind powerfully influenced their lives after being ill. One of the participants directly stated, "I think the mind is what matters." This statement indicated that how the participants thought about their sickness situation was important and led to their responses.

As one of the participants commented on feelings and situations:

"I think any ill person always feels discouraged and has no motivation. The more you feel this, the worse you will be. It caused a lack of confidence. However, I had already passed that feeling... I knew that it had to be like this. I came to terms that I had to accept what was happening to me now. I knew that I needed the treatments, so I came for the treatment regularly. I did not object to the necessity for the treatments. I did my best. I stopped questioning and being upset by what has happened."

Another participant explained how he adjusted his ways of thinking, and handled his illness situation. He stated:

"I realized the fact that I was sick, and I accepted it. People said that I might die when I first got sick. Some of them have already passed away, you know, many of them. I realize that everybody would die anyway and I am aware of this fact. Therefore, I stopped thinking too much about dying. I should live a meaningful life. I will do my best for the rest of my life."

This participant was young when he got sick. It was hard to accept the fact of what had happened to him at the very beginning.

The participants made a decision to move forward. They needed to face the reality. If the participants were able to accept their illness, they seemed to have less stress and be more at ease. As one participant said, "Dialysis delayed my deteriorating condition. I know that, and I accept that." This participant knew the fact that his illness is incurable, but hemodialysis is necessary. He, therefore, accepted the situation. He seemed to live his life with ease. In responding to his current state of health, he stated, "I am okay. I can handle it." Another participant who was the head of the family stated, "I accept my treatment right now. Life goes on. Whatever will happen I will let it go, let it be. I will continue on hemodialysis until I die." Although this participant was unable to work and had dramatic changes in his life, he seemed to be at peace. He felt a lot better than when he first became ill. After he had hemodialysis, he was satisfied with his general health.

However, approaches to accepting the reality of their illness varied among participants. One participant stated, "It had already happened. There was nothing, I could do about it. I let it be." Participants had their own rationale for their viewpoints. In addition, individuals took time, either short or long periods, to accept the illness. Some participants took a year or two to be familiar with their illness. One of the participants recounted her acceptance of her illness, "It took a couple months, it had already happened. There was nothing I could do about it, I let it be." The sooner the participants were able to accept their illness, the better they adjusted to their situation. Accepting the fact of what happened in life contributed to positive actions.

Learning about the disease and seeing other patients' problems also encouraged participants to accept their illness. As one of the participants stated, "I also see more patients

who are undergoing hemodialysis for many years, and they are still surviving. I think that is good enough for me.” When this participant learned that there were more people that were as sick as she was, she gained more information about the disease and its treatment. She was able to live with her condition.

Another participant thought that she was the only unlucky person at the beginning, because she had never seen other people who were sick with the same disease she had. She had been upset and regretted being sick for a long time. She stated, “Once I saw many people who were being sick with the same disease as mine, I changed my outlook about my situation. It seemed like I was not alone anymore because I saw many patients with renal failure.” Once she saw other patients’ conditions and appearances, she felt that her life was not that bad. She did not appear as ill at that time as did others who were experiencing pallor and weight loss. She said, “I saw other people suffered more than me. They had vascular access at their neck, I felt sorry for them.” Moreover, she also was happy that her vascular access was in her arm and not immediately apparent to others. When compared to others, she was happy about who she was and how she experienced her illness. Learning about the disease and seeing other patients, not only facilitated acceptance of the illness but also influenced participants to develop a positive way of thinking about their illness.

Developing a positive outlook. Trying to live a normal life with their chronic illness was challenging for most participants. Developing a positive outlook was an important component of trying to live their life as normally as possible. One of the participants thought her life was miserable at the beginning of her illness. However, her family, her children, and other patients’ lives influenced her way of thinking. She recounted that her life had changed from being meaningless to meaningful:

“I observed my peers, who had more serious problems than mine. They never gave up on dialysis. Some patients did not have money to pay for dialysis, but I had financial support. I started releasing my stress because I was in a better situation than others were. I realized that. Why I am still unhappy, I asked this question to myself. Right now, I am okay and I am not depressed. My family and my husband treated me right. They provided me hope to live. I have been getting healthier because I was able to eat more foods. I guess I became accustomed to my sickness.”

She considered herself a lucky person when compared to others. In addition, when she learned about other people's problems, she realized that her situation was not so bad. She had good sources of support such as finances, family, and work far better than many of the other patients. One of the participants, who experienced various illnesses before becoming an ESRD patient, demonstrated that her life was normal although she had to be on hemodialysis. She recounted, “Other patients always complained that they were fatigued after the dialysis, but I was fine. I still was able to work. My kids and my husband wanted me to take a rest, they turned the air conditioning on for me, but I can't help myself running some errands. I knew that what I could do, so I did not want to be helpless.” Her physical appearance did not look healthy to me, but her expression and her actions were opposite to my thinking. She experienced severe illnesses and various treatments throughout her life. Nevertheless, she never experienced regret or got discouraged. This participant seemed to be comfortable with her illness and satisfied with her condition. She recounted, “I was lucky that my vascular access still worked well although I did not get it done in Bangkok like others did.” Although her vascular access on her right arm was obviously noticeable, she accepted its appearance. She seemed to be proud of herself and appreciated how lucky she was that she was able to keep it working for four years until now.

Another participant expressed a positive outlook as she responded to the question of how her life had changed due to her illness. She said, “It changed in a good way. Although, I could not work, it was fine. It should be my resting time, it's my vacation...I had worked very hard,

now it was a time for me to take a break.” Many of the participants spent more time with family after they were ill. One participant expressed that it was a good opportunity that he could be with his grandchild. He proudly stated, “She [his granddaughter] loved to hang out with me more than her grandma...It is good that I can spend more time with my granddaughter.”

The participants’ outlooks led the ways they responded to their struggles. Their outlooks were somehow associated with their quality of life and their ability to make lifestyles change. This positive thinking became input for other positive actions that supported participants to find a way to live their lives.

Nurturing spiritual health. Participants tried to live a normal life as much as possible. However, illness severity as well as costly and time-consuming treatments of end stage renal disease created a stressful situation for them. Therefore, many of the participants sought to nurture their spiritual health. Religious beliefs, practices, and ritual ceremonies were used for a sense of being protected, stress reduction, and reducing feelings of destruction. These strategies helped them feel safe in various unstable situations.

Participants in this study had experienced suffering from their illness such as sudden life threatening or unbearable conditions that directly affected their lives. Therefore, they started seeking benefits in traditional religious beliefs and other practices. One of the participants was undergoing a painful treatment procedure with no success as the doctor failed to complete it. She begged, “Whoever please help me, I could not tolerate the pain anymore... I would share and distribute my good deeds to them through offering food to the monks. I promised to do that.” This participant believed that by making this offering, her request would be granted. She recounted that the doctor had completed the procedure successfully after she made her promise. Another participant asked for help when he was suddenly in a critical condition. He recalled, “If

I did not die, I was willing to be a monk at least seven days.” He was afraid of dying and he was willing to do what he thought would help him stay alive. He fulfilled his promise, his condition improved and he has been on dialysis for seven years since that event.

Many of the participants said that they never paid attention to religious practices until they were ill. They realized that they needed mental and spiritual support. Religion might be a good source of support they could rely on. One participant recounted:

“At the very first, it was horrible. I think too much about every thing... If I could not find a way to reduce my worry, I would have died. If I worried too much I could not go to sleep. If this had happened every day and night, I must have been very tired. My health condition might have deteriorated rapidly. I went to the temple. I got a good suggestion from the monk that I should start praying... Praying helped me get longer sleep.”

He started praying before bedtime, but he was unable to meditate. He said meditation was too difficult for him. He felt that only praying was helpful. He truly appreciated the monk’s suggestion because it had been beneficial.

Another participant recounted that he had sleeping problems. He had insomnia because he was so worried about everything. He had been using sleeping pills for a long time to put him to bed. Finally, he started reading Dharma book, praying, and meditating which helped him wean off taking the sleeping pills. Another participant started paying attention to religious teachings and practices, she recounted:

“Formerly, I was not interested in Dharma. Since I have had this disease, I was interested in Dharma and Buddhist practicing. What I did was, I strictly followed the five commandments of Buddhism, and I never broke any of the basic precepts. I began to pray by myself. After regularly praying, I motivated myself to manage time to pray everyday.”

This participant found these practices helpful. Although she had been sick for four years, she was still able to work fulltime and had even started a small family entrepreneurship. She made and sold crispy rice cakes on the weekend. She said that having more free time might have possibly created worry and anxiety for her. A little extra work occupied her free time. Therefore, she did

not have time to think of or worry about her illness. In addition, she also gained some money to support the family's expenses. She admitted that this strategy worked very well for her and helped her to live a normal life. Another participant also demonstrated that she benefited from religious practices. She said:

“I prayed every night and it helped me have a clear mind, stay calm, and accept the reality of life... Sometimes, I got angry or mad. Whenever I realized those destructive feelings, I would warn myself. I tried to be aware of what I was thinking and doing. For example, when I was moaning with pain for a while as soon as I gained consciousness I would tell myself why I did that. It was painful and even if I moaned it would not go away, but it made other people worry about me. I mean my husband and my daughter.”

Another participant also tried to embrace some ritual practices into her daily life, she said, “I prayed and meditated regularly and led a chant for my mom at night because she could not see very well. Sometimes I did chanting while driving to work. Whatever I could do, I would do it.” Many participants seemed to see good benefits from their practices. Therefore, they tried to follow the religious teachings. As one of them said, “I tried to be aware of what I am thinking and doing.” The participants had somewhat basic religious practices. However, they had their own way of doing their practices. One of the participants recounted, “I prayed in the early morning. Because in the evening, I felt like I had a low battery and was tired. I wanted to rest. After I got enough sleep during the night, I woke up and prayed early in the morning.”

Since all the participants in this study were Buddhists, their ways of thinking and actions were associated with the Buddha's teachings. The law of karma, for instance, whatever one had done in the past would affect a present and a future life, is one of a Buddhist's principles. One of the participants believed that her illness might be associated with her bad actions in her previous life, because she could not think of any sins in her present life that might cause her to be an ESRD patient. She said, “Since I was ill, I tried to do good things. I tried not to hurt even anyone's feelings. I believed that if I hurt someone, I would be cursed. I followed the five

commandments of Buddhism; therefore, I did not have any destructive thought or do harmful behaviors to anyone.” Another participant said, “I try to do good deeds and not to do anything bad that might hurt others.” Believing in the law of karma, participants restrained doing any bad actions, but accumulated as many merits and good deeds as they could for their future.

Many of participants in this study had already had a ritual practice in their daily life and they continued or even paid more attention to it after their illness. As one of the participants recounted, “I offered food to the monk every morning.” She has been offering food to the monks since she was young. It was part of her routine life. Another participants said, “I cook foods and offer it to 10 to 11 monks everyday. I have been offering food to the monks since my kids were young. ...but we did not go to the temple. We prefer offering foods to the monks instead of going there.” People who live in rural areas, traditionally offer food to the monks to teach basic religious practices to their children. They do that as a part of their daily lives. He continued, “In addition, we also offered food to the Buddha image at our houses. My wife prepares food for the Buddha image at this house because the shelf is very high and she did that to prevent me from falling down. I was responsible for preparing food for the Buddha image of another house.” Moreover, some participants also offered food to ghosts or unseen beings and prayed that they would protect them from any harm.

Although participants had to live with their illness, they were aware of worthy living. Therefore, sacrificing something was also one of the common practices that the participants were willing to do. One participant said, “If I could make other people happy as well as me, I would do. If it is useful for others, I am willing to. I do not know when I will die. I want to be helpful. If I could do something that is useful for others, I am happy to do so.” Their sacrifice varied depending upon their beliefs and their potential capabilities. If they were able to do something

that might be useful or helpful for others, they were happy to do it. As one of the participants who applied religious practices in his daily life, recounted, “I would help anyone if I could help. I did as much as I could, you know. In my neighborhood, I took the sick to the hospital because I have a car. Whoever needed help with an electrical problem, I would fix it for them at no cost. I did whatever I could to help, but I did not give myself a hard time.” Once the participants had started religious practices, or sacrificed something for quite some time, they felt these approaches were useful. They felt good about themselves.

Participants wished to gain benefits from religious practices, being a good person, and doing good things, which they believed might have something to do with their illness that they were dealing with. “I made a merit as much as possible. I believed in that. The merit might help me somehow.” In addition, participants realized that they might not be able to live their lives as healthy persons, but it was still worth living. Therefore, they would try their best to live their lives by maintaining and enhancing physical, mental, and spiritual health as much as possible.

Adjusting their Lifestyles

Participants set their state of mind on living their lives. A wish for all participants was being back to normal. They had to take charge of their illness. Adjusting their lifestyles was very important in order to live a normal life and compromise with disease and treatment protocols.

Seeking care and support. Due to a limited number of hemodialysis units and their unequal distribution in Thailand, the ESRD patients who lived in remote areas had difficulty gaining access to treatments. Participants tried to access care in many ways. Some of the participants had to move to where they could access care either through physical means or through their eligibilities. They had to move to gain medical benefits or to gain social support.

Many participants had to change residency to a location that was more convenient to access care. One participant stayed with her older sister's family. She said that her hometown was about a 45-minute drive, but she had no car. If she had to take a public bus, it would take a longer time. Therefore, she stayed with her sister, which was more convenient for her because she was able to walk to the dialysis unit. Her traveling time was far less than staying in her hometown. Moreover, she could save time and energy to run some house errands that helped her sister. She had quit her job since being ill and she was unable to apply for a regular job anyway. Consequently, her medical expenses were now her sister's responsibility. She said, "I am very close to my sister, she helped me as much as she could...I paid 300 baht extra for a five-hour hemodialysis, and 200 baht for a four-hour session. It meant I paid 500 baht a week. I am okay with that."

Another participant was unable to work after her sickness and lived with her family in another province, where there was no dialysis unit. This participant also became a burden to her family. She recounted that her mother rented a room that was close to the hospital for her to stay in while she started the treatment. She could go to the hospital herself instead of asking one of the family members to give her rides to the dialysis unit two times a week. She remarked that asking someone to drive her to the unit was time consuming, and the cost of gas might be a lot more than just paying the rent.

Another participant, diagnosed as a SLE patient prior to having hemodialysis, decided to move back to her hometown after her sickness. Since she knew for sure that she really needed close medical attention, she moved back to her hometown where she had a place to live without paying rent. In spite of living in an old shack, it was still her best option.

Not only changing residences, but also dealing with a commute to receive care was an issue. As one of the participants said, “After I got sick, I moved and stayed at my wife’s house... While staying in his wife’s hometown was better than where he used to live, it was still inconvenient to go to the dialysis unit.” In a rural area, the buses were very rare. There were only a few buses available in some small villages. Therefore, this participant came to the dialysis unit by a school bus in order to be at the dialysis unit in the morning.

Most of the participants in this study came to the units by public buses. One of the participants said that the night before his dialysis schedule he had to stay with his daughter in order to go to the dialysis, which is easier than staying at his own house. However, he had to connect three buses along the way to the unit. In addition, the bus schedule was not a fixed schedule, the bus driver usually waited until there were enough passengers for each trip. Participants had to be at the bus stop earlier than they were supposed to in order to ensure that they would get to the dialysis unit in time and did not miss the bus. After their dialysis sessions, which would range between four to five hours, they had to catch the bus to go back home as well. Therefore, a whole day of their time was spent getting hemodialysis. The participants were not able to do anything else. In addition, participants also felt weak after their long dialysis sessions, and they needed rest.

In spite of having their own cars, some of them were unable to drive due to their condition. One participant said, “Whenever my hemodialysis schedule is, the hospital ambulance will pick me up to do the hemodialysis... My children were afraid that I might faint when driving, they took away my car keys.” Participants were tired after a long hemodialysis session. If participants had cars, their travel seemed to be much easier; however, they still encountered other problems. As one of the participants recounted:

“I live quite far from here, you know. I could not come by myself; I always hired someone to drive for me. My husband and my daughters have to work. If they don’t work we don’t have money. I have an old car. Whoever in the neighborhood who is available will drive for me, I paid 150 baht for a driver, and paid for filling up the gas.”

Due to her physical weakness, living far away from a dialysis unit, inability to drive, and financial limitations, this participant struggled with many problems. This participant needed somebody to drive her to the units because she received the treatments from two dialysis units: a unit at a private hospital and another unit from a non-profit organization. Even though going to the non-profit unit was far away and difficult, she needed to go there because the cost was cheaper. In addition, she had no health insurance or any other financial support. She tried to find a way that was the least financially damaging to her situation. Since her husband had to keep working in order to gain the money for her treatments. She continued:

“If the driver cannot help me with getting my medicines, I had to hire another person to help me with this or ask my husband to come with me that day. I had to be on hemodialysis for 5 hours, and when I finished the session, that person would get my medicine around the same time. So I could go back home because it had been a long day for me.”

Participants, who had cars, still needed drivers. They mostly came to the unit by a family member who gave them a ride. One participant said, “My son- in-law had to drive me here and then he had to wait here for 4-5 hours.” It was a one-hour drive each way to the unit. She said that it was more convenient for her than taking a bus, but she still felt that she was a family burden because she could not come by herself. Her son-in-law as a driver and her daughter who always was her company, spent at least six hours two times a week with her when she had hemodialysis. Transportation was one of the difficulties of accessing medical care that participants had to deal with. The transportation obstacles among ESRD patients could be physically, emotionally, or financially problematic depending upon the individual’s situation.

Adjusting dietary and fluid intake. The limitation of fluids and diet was unpleasant for most of the participants. One participant said, “At first, it was frustrating because I could not eat many kinds of fruits that I loved. Meat also was limited. It was a discouraging situation.” Since food consumption needed to be changed after the sickness, participants tried to adjust eating and drinking styles in order to live with their illness. It was very interesting how participants coped with dietary and water restrictions. One participant said:

“I learned about diet for dialysis patients from the posters posed in front of the unit. I was very strict on what I should eat or should not eat. I was too concerned about diet. For now, I am not worried about it anymore. I eat what I want to eat. If I want to eat pizza, I will order it. People have to eat food for survival. Normally, I was not easy about foods. I like fruits and vegetables. Well, since I have had this disease, I cannot eat very much of fruits and green vegetables.”

Most of the participants were more careful about diet and drinks, but they approached this issue differently. Among low-educated participants, they were not able to explain why they need to restricted some specific food, but they had done it the right way. As one participant said, “I try to take care of myself. I try to stabilize my conditions. I don’t know what to do next, but I have already stopped eating many kinds of food and fruits. Since I have known, they are toxic to me.” Another participant explained, “I am always aware of eating, I am not a normal person. Therefore, I warned myself about my sickness. If there was something that I was doubt of its effect on my body, I would not take the risk.”

Some participants were able to search detailed information about how to take care of themselves and understand why they had to limit eating and drinking, but some needed suggestions from healthcare personnel. One of the participants seemed to be confident coming up with her strategies. She recounted:

“I focus on my foods and drinks. I limit my drinking water to no more than a bottle. I have my own 500 cc bottle, and I carried it wherever I go. I prepare my drinking water by myself as a routine. It is ‘a must’ for me to do so. I do not drink more than 500cc...I

did whatever seemed to be good for my health. I searched for more information. I read, asked, and went everywhere if I thought it might help. I spent a lot of money to maintain my health. I tried everything such as herbal food or medicines, traditional Chinese medicines, dietary supplements, and etc.”

In contrast, some of the participants learned by their direct experience. One of the participants recounted, “I have learned my lesson since eating the banana, I’d never dare to try it again, not even a bite because I know that I would be in trouble. It scared me to death.” He ate one of the bananas from his own garden, which he loved. He used to eat it as a snack whenever he was hungry. This participant did not know that bananas would cause him problems. After eating the banana, he was sent to the emergency room because he had difficulty breathing. He said he would have died if nobody took him to the hospital in time.

Another participant recounted his direct experience of eating fruit. He said, “I was sent to the hospital at night once because I ate durian, I thought I was going to die. I hardly breathed. My brain did not work. Since then I have never ever eaten durian again.” Many of the participants were concerned about food either because they had eaten some of the foods and became ill or because they were given specific restrictions. However, learning from direct experiences was one of the most powerful lessons that provided a life long knowledge and insight understanding.

Some participants dealt with diet restriction aggressively. One of the participants was very concerned about his diet and did not want to take any risks, therefore; he cooked the meals by himself. He said, “I always cook for myself because I know what is good and what is bad for me. I choose whatever I can eat... I do not eat anything that tastes very sour and salty. I avoid putting any kind of seasoning on my food. If I really needed it, I put a little bit of fish sauce but not too much.” On the other hand, some of the participants could not do much about their diet. As one of them recounted, “I reduced eating fruits. However, I could not help about my regular

meals. I have to eat whatever the rest of my family ate.” This participant dealt with his diet in a relatively passive way. His meal depended upon the one who cooked.

After being on hemodialysis for quite some time, the participants knew what was good for them. For instance, what kinds of food they could safely eat, how much and when they should eat. One participant said, “I eat rice one cup daily. Just to be full but not too much. When I see people that eat a lot, I feel concern of them.” Another participant talked about how to eat the food she loved, she said, “Now, I was well adapted to my eating. What I did was I ate anything I like on the days that I had dialysis. Just like today, I ate fried bananas when I was on dialysis. I have no problem with my diet.”

Participants were able to be in-charge and adjust their drinking and eating styles that compromising with individual preferences and illness protocols. As one of the participants concluded, “I drank only a half glass of water after my meals- no drinking water between the meals. I did not measure it. I estimated it. However, I never had any problems on my drinking at all.” Participants controlled their diet in various ways depending upon individual situation. However, there were some similarities of dealing with food cravings. Another participant also said, “I always ate just a small amount. Just to feel that I had already eaten the food I like. I would not eat much even though the food was very delicious.” These participants were able to handle their restricted diet very well. Another participant, who had undergone hemodialysis for seven years, explained how she normally approached her practice of drinking water. She said, “When I am thirsty, I will have a small piece of crusted ice. I will drink a lot of water only when I have to take my medicine. Otherwise, I will sip plain water. I noticed that the more I drank cool water, the more it would make me feel thirsty.” She recalled that she did not have any complications from fluid overload after her first two years of treatment. She said that she learned

her lesson and knew how to avoid problems. She was proud of herself, that she was able to be on hemodialysis for a long time. She also recounted, “My theory was I ate anything that I like, but I would take just a few bites.” Dealing with diet restrictions in this way reduced stress regarding dietary restrictions. When she had a craving for a particular food, she ate a little bit. This strategy empowered her, and she felt that her life was still relatively normal.

Not everyone was satisfied and successfully dealt with diet restriction; some of the participants had difficulty dealing with it. One participant considered herself as non-compliant. She aggressively followed her desires for foods although she knew that the foods would cause her problems after eating. Her response on fluid and diet regimens was a destructive strategy to her illness. She recounted:

“Soda is my favorite, it is a prohibited one, but I could not help myself from drinking it. Other food I also ate, I really wanted to eat whatever I liked. I could not stop myself on eating; I ate a lot of food...I bought the food I like from the market and hid it from my parents. I ate it in the hallway to hide from being caught...I know that white egg is good, but it does not taste good at all... I ate white eggs sometimes, but I barely ate fish. I do not like the fishy smell. However, my mom cooked and forced me to eat it”

Her problem was she could not compromise the rigid diet regimens. She had conflicts with both fluid and diet restriction. She drank a lot of beverages and water. She explained:

“I always feel thirsty, I do not know why. I always drink a lot of cold water. I drink cold water all day...I could not take even a small piece of ice cube, I felt like I was going to throw up. I needed to drink water. I meant a whole glass of water. My mom and my dad scolded me if they saw me drinking a lot of water, but I could not help myself from drinking water.”

In addition, she continued eating many kinds of food that she was not supposed to eat. Therefore, she always had a problem of fluid overload. She said, “It happened very often because I love to drink a lot of water. If I could not stand it I would call to set up my dialysis session sooner than my normal schedule.” This participant’s challenge was changing her eating style. It was hard for

her to change her eating habits and desires to fit her illness. Although her family tried very hard by encouraging and supporting her. It seemed that her husband and her family were more concerned about her diet than she was. She recounted that the only thing that was an arguing issue between her and her husband was food and fluid restrictions. She said, “The issue that we did not agree on was my eating because I love to eat food. He is more concerned with what I should eat than I am. To me, I just followed my desires. He felt sad if I suffered from eating.”

Unlike the participant above, one of the participants who also loved drinking soft drinks and juices dealt with the limited drinking differently. He recounted how he dealt with his drinking water. He said “[He drank] A bottle a day. [It was] a half-liter bottle. Sometimes, I empty it, sometimes I don’t depending on the weather condition. The forbidden drinks I sometimes drink ‘Pepsi’.(Laughter). Just to feel fresh” He put the juice he loved in the freezer and he would suck the juice from a small piece of ice cube instead. He rarely had problem with his drinking water. Many of the participants loved soft drinks and learned to cut the amount of their drinks. Another participant stated, “I felt crave for drinking ‘Mirinda’. I drank a whole bottle by myself once. After awhile, I had to call my next-door friend and asked for a ride (motorcycle) to the hospital... I did not do it the same way again. I poured it in a glass. I just drank only small amount, I gave away the rest to my friend next-door.” The participants knew that some food or drink would have negative affects for them. However, they had learned to adjust the amount or to apply using something else for the food they were craving.

Overcoming Financial Struggles

Hemodialysis was necessary for all participants, but the cost of the treatment was high, Therefore, financial insecurity was a common struggle. Participants needed to find a way to deal with this problem. They responded to their economic problems in various ways.

Gaining support from their families and friends. Participants received monetary support from many resources, such as spouses, siblings, friends, and workplaces. One participant received 100% of her health coverage from her husband's work benefits. However, they had to provide cash for each medical visit. She said, "Sometimes, we had to borrow some money from our relatives when we were broke because we had to pay for my treatment up front and then received reimbursements later." It was not surprising that if the participants had no health insurance, their financial problems became more severe. As mentioned by another participant, "At the beginning, I needed a lot of money for the treatments. All of my siblings helped me with my finances." This participant stopped working and had insufficient income to support her medical payments. Luckily, she has a big family and her entire family was willing to help her by offering her some money for her medical expenses.

Some participants gained support from outside their family. They gained social support from friends, co-workers, or even health personnel. A single young man who quit his job and stayed home with his mom after he got sick indicated, "I have many good friends, they loaned some money to me when I needed it." Some of the health personnel were generous and paid for patients' treatments. One of the participants recounted in tears, "Sometimes, the nurses of the unit paid for my treatment."

When some participants had no money to pay for their treatments, they tried to borrow money from wherever they could. One participant recalled, "Sometimes I had financial problems. When I could not work, I had to borrow the money from someone else; that was my problem." This participant had to borrow money from somebody else because all of their relatives also were poor. When asked if there was any support from family, another participant stated "Yes, but it was very rare, because my relatives are also poor. Sometimes I had to pay

interest [on my loans], but I usually paid them back as soon as possible. I mean, not more than a month. I did not earn enough money to pay my bills in time.”

Participants who were relatively poor seemed to become more in debt because of the expensive treatments. Additionally, many participants were in debt even before getting sick because they did not earn enough money for their cost of living. Therefore, their financial situation was even more difficult. One participant worked as a laborer that was paid minimum wage. She suffered from monetary problems. She softly said, “We did not earn much money from our jobs... I cannot even work now... My husband did not have a regular job. He would work if someone hired him.” She and her husband were both non-skilled laborers. Earning money was insecure for this couple depending on the weather, demand for labor, and their ability to work. If it rained or they were sick, they were unable to work, it meant they had no money. She recalled, “My husband had to borrow some money for my treatment.”

One of the participants stopped working after getting sick and became dependent on her father. She whispered, “I just got married to get free medical services. Actually, he is one of my relatives.” Her marriage was a secret, therefore, she whispered when telling me her story. It was a dilemma situation. Her official marriage attempted to gain healthcare coverage benefits. She and her family faced financial difficulty. For a year of her treatment, she had already used up a large amount of money for medical expenses that her father borrowed from his workplace agency.

Trying to apply or continue eligibility for health insurance. Some participants did not have any health insurance before getting sick. They tried to get insurance that would pay for their hemodialysis, such as social health insurance, or joining the 30-baht program. Some of them, who had social insurance before their illness, tried to continue their eligibility. One participant

stated, “I quit my job, but I still paid for my social health insurance.” These efforts would help them pay some part of the medical expenses. For example, they would get cheap medications just paying 30 baht per visit, or the social insurance would be responsible for a certain amount of money for the hemodialysis, and participants would pay the rest of it. One participant explained how the social insurance worked, “The social insurance gave me only 1,500 baht per visit, but not more than two times a week. I paid the rest myself... It cost me 1,700 baht depending on the type of filters. I used a very simple one. If I used the better one, it would cost me more. I paid 200 baht per visit, it cost me 400 baht per week.” Participants paid for not only the treatments, but also extra cost of living related to access to care, for example, food, transportation, and rent.

Cutting down their personal and medical expenses. The participants reduced their cost of living in order to be able to pay for their treatment. One of the participants who usually paid a lot of money on her beauty care recalled her past: “I always took care of my face very well, but I changed after I did the hemodialysis. I stopped everything. I did not want to do it anymore. I should save money for the dialysis. My treatment should be the first priority.” Another participant who had no health insurance tried to lower his expenses on the treatment in many ways. He stated:

“I tried any possible ways to reduce my expenses, such as getting my medicine from the government hospital, where I had to pay only 30 baht per visit. I bought glucose that I needed for the dialysis from a drug store because if I bought them in a dozen it was cheaper than the price at the hospital. I gave them to the nurse when I have to do the hemodialysis. It was nice that they let me do that; I could save some money.”

After paying a lot of money on the hemodialysis, many participants had no more money to afford further treatment. Therefore, they tried many strategies in order to survive with minimum medical costs. Cutting down the frequency of treatments was one of the participant strategies. As one of the participants recounted, “If I did not have money, I would cut off the

treatment. Instead of coming twice a week, I would come only once.” Another participant illustrated his attempt to cut off the treatment as much as he could physically tolerate. He recounted, “It was hard to borrow money from someone else so I had to do dialysis less than before. Later, I reduced it to once a week, but I could not stand it. Finally, I changed my dialysis schedule to once every five days.” Even doing that, he still encountered financial struggles. He also planned for his future that he might stop hemodialysis, and switch to peritoneal dialysis instead. It was obvious that the participants tried to live their lives under individual limitations. They would do whatever they could to continue their life, such as searching for a cheaper treatment.

Non-profit dialysis units are very rare. According to the participants’ knowledge, there was only one non-profit dialysis unit founded by the royal family for low-income patients. This unit is located in another province. The cost of each dialysis session here was about 50% less than the cost at the private hospital. However, the access to treatment was limited due to long distance, the number of machines and health care personnel. There was a long waiting list; one of the participants had to wait more than a year. Although the dialysis cost was cheaper, traveling to this dialysis unit was inconvenient. One participant said that she had to be ready and leave her house at two in the morning twice a week. She had to show up and get a cue number at the dialysis unit early because it was on a first-come-first-serve basis. By going there, she was able to save some money, she explained, “I went over there seven times a month, so I paid 7,000 baht over there. I came here once a month and paid 2,000 baht each time.” She managed to get a cheaper treatment as much as possible. Therefore, she went there seven times and came to pay a regular cost only once a month in order to see the doctor and get the medicines. Since this participant was not eligible for support from any health insurance, she tried to reduce the expense

to how much she could afford. She stated that her husband personally went to ask the director of the hospital to lower the dialysis cost for her because she could not afford it any more. However, she paid a lot of money on her treatments. She sadly recounted, “We used up our savings money and we had already sold two big parcels of our land.”

In summary, most participants faced financial problems under various circumstances. In addition, the severity of problems varied and fluctuated. Despite their illness progression, the participants had to fight with other struggles. However, participants found creative strategies to deal with each situation.

Consequences: Life Goes on

After coming to terms with being ill and knowing that their life would never be the same, participants set their mind on how to live their lives. They learned about their illness and dealt with their individual situation. Various good and bad experiences facilitated them to be able to live with their illness. They came up with strategies to preserve their pursuits and their lives. Participants learned and knew who they were through their direct experiences. Some were successful and satisfied with adjusting their lifestyles and dealing with problems. Some still struggled with many ongoing problems. However, a major theme that explicated the consequences of being Thai ESRD patients who were undergoing hemodialysis, was “life goes on.” It was a sentence that came from participants who tried to explain how they lived their lives. One of the participants said, “Life goes on. Since we are alive, we have to fight for a living.” This statement was prominent in the participants’ minds and was the clearest explanation of why and how they lived their lives. In addition, there were three sub-categories: a sense of normalcy, a sense of self-worth, and on going struggles that created and facilitated “life goes on.”

A Sense of Normalcy

Participants had already accepted being sick; however, they still experienced a wide range of unstable symptoms and their severity. They had to deal with them all. Participants gradually knew and learned to solve their problems. One participant recounted, “Whenever I experienced or suffered with some weird symptoms, I always asked other patients if they have ever experienced or not.” When participants figured out that they experienced similar problems as others did, they felt relieved. In addition, patients were able to learn from one another. As one of the participants said, “I noticed that many patients wore socks although the weather was not that cold. I learned that wearing socks helped them to prevent and reduce pain on their feet.”

With the intention to live a normal life, participants would take charge of their living. They learned to look closely and listened to their body. As one of the participants said, “I would pay attention to my blood test as well as my symptoms. If I found that I had something that was not quite normal I would check it out. I want everything to be under control as much as possible. However, I am not in a panic.” If participants had ever seen other ESRD patients experiencing the same condition that they had, and these people were still able to take care themselves. This created a sense of normalcy and a feeling that they were not alone in this world. In addition, if others shared the strategies they used, which were successfully in overcoming their struggles encouraged and supported the participants’ hope of continuing to live their lives.

Although sick, many of them expressed that they felt normal. As one of the participants said, “I think I seemed to be normal. I think exercises also made me feel good and look normal. It was hard for others to tell that I was sick.” Responses to questions of how participants thought about their current health, one of the participants said, “It is normal. It is good. It is all about the

way of thinking, you know. I have to be happy. I don't think about my sickness that much. When I first had it around 5-6 years ago, I really wanted to die. I was depressed."

Another participant reported that she was normal because she was able to run some errands for the household on the day that she did not have dialysis treatment. She said, "The day that I didn't have to do hemodialysis, I felt I was normal. I could do my housework as usual. The only thing that reminded me about my sickness was my arm[vascular access lesion]."

In responding to how the participants lived their lives, one of the participants directly said, I tried to normalize it. My daily life became normal these days... I have never eaten anything that made me go to the emergency room or had to come sooner than my scheduled treatment." The participants lived their lives relative to their capabilities. They seemed to accept their condition. Another participant, who was well adjusted in his life, proudly said, "I could play sports I like on the next day after hemodialysis, such as, ball, soccer, and swimming. I could do anything. If I had free time on the weekend, I sailed the boat to catch fish in the river." He definitely tried to convey that he was able to live his normal life.

Having sensed that they were normal, participants continued to pursue their individual goals, such as trying their best and living happy lives with their families. One of the participants, who was the only son and had been sick for 14 years, desired to be with his parents as long as possible. He felt sorry for his parents because they had already paid a lot of money for his treatments. If they had not spent this money, his parents would have been very rich and lived very happy lives. Therefore, he thought that he should at least survive and enrich their lives. So far, he had done very well. He said, "I am satisfied with how I am doing for now. Although I need hemodialysis, I feel I am normal...I would give myself a score of eight out of ten." He said that his parents sacrificed much when he was very ill, which was a great motivation for him to

get better and find a way to live with his illness. It is typical in Thai society to show heart felt gratitude to parents by taking care of them when they are old. As another participant said, “I stay with my mom. I want to be with her because she is getting old... I'm happy to be her company because my dad had already died. It is good that I stay with her. We only have each other.”

On the other hand, being able to be with one's children also had a positive influence on participants and help them to live a more normal life. One of the ill fathers said, “Having a son is an encouragement and a good source of support for me.” He had been very ill since his son was only two months old. At that time, his goal in life was to continue working and to take care of his young son because he was the head of the family. His responsibility and determination contributed to extending his life span because he looked forward to his family's future. This participant had been undergoing hemodialysis for seven years.

Financial contribution was very important if participants were a family leader. Therefore, many participants kept working, either the same job or finding a new one that fit their situation. One working mother became sick when her son was only seven months old. This participant still kept her job, but moved to a place where she was able to access medical care and gain family support. She had to travel a long distance to work and to receive dialysis. However, she adjusted well and lived a dynamic life without thinking of the disease as a burden that affected her. She said, “Renal failure became a part of my life... I thought about myself, I realized that I was luckier than many of the patients. I am still able to work. I have health insurance and a wonderful family. Something like that made me feel good.” She had a busy schedule working a full time job and taking care of her children and herself. She still did some trading at an open market after work or on the weekends. By doing this, she earned more money and was able to make a good living and have a meaningful life. Her goals in life were to take good care of her children and her

parents. Many participants' goals in lives were not only to be with families, but also to positively contribute to their families' well-being.

Even if participants were unable to work, they were still emotionally able to support their family. Elderly persons, especially parents and grandparents, are highly respected in the family. Families with elderly members at home feel they have good sources of mental and spiritual support. Having a sense of normalcy played an important role for participants to continue living. Capabilities to work or attain role responsibilities that contributed to their family created a feeling that they still had a normal life.

Improved physical function and prolonged living were participants' ultimate wishes. Therefore, the possibility of a renal transplantation tremendously inspired many participants. One of them remarked, "It is my duty to take good care of myself. I have to be ready for transplantation whenever it is available... I hope my wish of having kidney transplantation will come true very soon." She had a strong hope of obtaining a renal transplant. The transplantation was the best option for many participants. They felt that a transplant would help them to feel normal again. If things were normal they could do and be everything they use to be before they became ill. Returning to normal and resuming their previous life style would assist them to be useful and valuable to their family. Another participant recounted, "I also thought that if I had a chance to get a renal transplantation, my life would be back to normal again." The transplantation seemed to offer a bright future for them.

A Sense of Self-worth

Apart from pursuing goals in life and feeling responsible, feeling good about one's self was also an outstanding perspective of many participants. What participants saw and felt about themselves made them feel proud and facilitated them in overcoming difficult situations. One of

the participants demonstrated that he had a good attitude about himself. He said, “I am able to encourage myself. I always warn myself that if I did not care about myself, who would? ... Mostly I have to take care of myself. I feel good about myself.” This participant was very confident and had a strong self-positive outlook. Another participant said, “I am in a good condition. I have injections twice a week, but some patients have to receive it more often.” This participant was able to see a positive side of her treatment. She had a good attitude about her condition. Learning about other patients’ problems also influenced a participant’s way of thinking. She stated:

“Struggles in life are normal. Many patients had their own problems such as economy, unemployment, or family problems. Some of them had to live alone when their spouses decided to leave after they were sick. I thought about myself, I realized that I was luckier than many of them.”

This participant indicated that she felt good about herself and she saw her illness as a part of her life. She concluded, “Renal failure has become a part of my life.”

Appreciation of what had happened in life and feeling proud of selves motivated many participants to move on. One of the participants had been undergoing hemodialysis for 11 years. He had been struggling with his finances because his insurance did not cover his dialysis treatment for the first two years. However, he gained extra financial support from his work. He said, “My company supported me for many hundreds of thousands baht a year.” He further concluded, “I think the mind is what matters. In addition, my mom and my sister love me, and worry a lot about me. Their support is encouragement for me. Furthermore, my colleagues at work also understand and they all are good to me. Everybody tried to help.” He gained support mentally and financially from family and his work place. He had worked at the same company before being sick until the time of the interview. This participant’s abilities to see what had

happened, gain good support, and deal with struggles were something that he was very proud of and increased his sense of self-worth.

Another example of difficulty in life was withdrawal from family and friends. One of the participants experienced severe depression. He never wanted to see or talk to any one, but his family and friends paid close attention to what was happening to him and aggressively attempted to interact with him. Finally, they found a way to help him out of the problem. He learned that he could not lock his feelings inside and continue to be depressed with his illness anymore. He tried to do something that he liked. He recounted, "I like reading cartoons, listening to the music, and watching TV, particularly comedy shows. These made me laugh and feel relaxed." With the help of his family, he regained his sense of self worth and felt he could overcome the difficulties he faced.

When being asked about sexual relationships after being diagnosed, participants seemed to accept and be satisfied with their lives. However, some participants hesitated to start having a serious relationship and a married participant did not expect to have a baby. As one participant said, "Since I have to do the hemodialysis like this, I don't know how long she [his girlfriend] will be going to stay with me. Maybe we might not make it. However, I am not worried. I think that I can live alone. We are dating now; I am not sure about the future."

Participants were concerned about their sexual relationship, but they did not view it as a serious problem. One participant expressed, "The disease made my sex life slow down. I meant my feelings were the same, but my physical conditions were not ready for that. I told my wife straightforward. She understood and accepted that, therefore, I always spent the night in my kids' room." Although important, this aspect did not seem to negatively influence their sense of self-worth. Another married participant responded, "It seemed normal. However, we decided not to

have another child. Because of my illness, I am not sure if my child would be healthy or not.” Ironically, one of the participants stated that he and his wife had conceived a second child and she was five months pregnant. It was unexpected. It just happened naturally, but he was happy with that. He said, “I read about symptoms from the book, usually the patient has lost libido. To be honest, I have the same feeling about sex as I used to. Other people teased me, how I could make it despite I am sick.”

Ongoing Struggles

Since the disease is chronic and incurable, participants’ physical condition was unstable and fluctuated. As one of the participants described her condition, “Now, my health is bad almost everyday. My heart pounds rapidly and irregularly. I know my health status is not stable but I try to do something that I can live with it. I tolerated all bad symptoms.” This participant had been with hemodialysis treatment for seven years. Despite the fact that participants knew that lived with uncertainty, she was satisfied with her life. She constantly had to deal with her progressive illness. Another participant recounted how he experienced health problems:

“I had experienced many sicknesses and had surgeries all over my body: removal eye lens, removal kidney stones, surgery at my neck [parathyroid], and preparation for vascular access. In case, I am able to stay longer and if someday this vein fails to function, where I will get another cut for the vascular access. These days I try to relax, and my family understands that.”

This participant also expressed feeling regarding uncertainty situation. He had already dealt with various health problems, and he was still concerned about a possible complication.

Kidney transplant was a preferable treatment; however, it was not accessible for everyone. Age and financial situation seemed to influence participants’ degree of hope of obtaining transplantation. One participant said, “I wished to be better. I used to think about renal transplantation, but patients about my age I don’t know what would happen after the operation.

The expense for the transplant was also very high. I am not sure if it is worthy doing it.” It seemed that participants who were still young and had good finances had a sense of possibility to obtain transplantation. However, there was other concern beyond monetary issues. One participant recounted:

“At first, I planned to get a renal transplantation. My daughter would be a donor. We had done everything, such as blood tests and tissue compatibility. However, it was difficult to set up the operation. There was a long waiting list. I felt sorry for my daughter. I did not want her to be hurt. I thought a lot about this; therefore, I changed my mind.”

He changed his mind because he was concerned about his daughter's health and her future. He was afraid that his daughter's health might be compromised with only one kidney. Therefore, he declined the kidney transplantation.

Some participants dreamt about obtaining transplantation, but they knew that it was impossible for them, and their hope diminished. One of the low-income participants expressed, “Oh you know even living our normal life, we still had financial problems; I cannot imagine how hard my life would be if I had renal transplantation.” In general, the family and financial supports were necessary for participants’ lives; these supports also created a sense of hope to receive renal transplantation. Another participant who became financially dependent said, “I think my daughter and my son cannot afford it. Therefore, we never talked about this.” It was desperate situation, since some families were already had barely enough money to buy daily food. Their deteriorated health status and low educational status made these participants unable to maintain their regular labor jobs, or find other jobs. Their incomes were unstable before their illness and the situation worsened due to expensive treatments. Many of them were in debt. These were already impoverished, and the hope for transplantation seemed unrealistic and unattainable.

Even for participants who tried to maintain their good condition and balance their life, their health was unstable, and their finances were insecure as well. One participant expressed, “The longer I stay [alive], the more money my family has to spend on me. I feel discouraged. I had used up my family's money. I felt so sad when my mother sold some parts of our house.” This participant became a family burden. She sadly recounted that she should have not started the treatment at the first time, so her family would not face this ongoing financial problem. Financial insecurity was still the participant’s ongoing concern.

One of the participants expressed his worry and anticipated that his finances might get worse in the near future. He sighed heavily and said, “If I do not have money anymore, I have to stop hemodialysis. I will do the peritoneal dialysis instead.” Similarly concerned about finances, another participant stated, “If I did not have money, I would cut off the treatment. Instead of coming twice a week, I would come only once.” This participant had cut off his treatment for a while. Fortunately, this participant received hemodialysis free of charge once a week later on.

Although many problems still existed, particularly financial problems, participants were able to reduce the degree of their severity. As one of the participants recounted, “Sometimes my husband went fishing or trapping rats from the rice fields. These were two sources of protein for us. If he got many fishes, he would sell them and save money for me to pay for the dialysis.” Although this participant struggled with financial problems, she was able to live her life as a good mother. Her financial stability was a short-term goal. By using a little trick on paying bills, she had money for her dialysis each week and paying insurance bills to maintain her eligibility. She delayed paying the insurance company bills for two months. When the third month’s bill came she would pay the first month’s bill off, but she still owed the company the second and the

third month's payments. If she did not pay any bills for three months, she would not be eligible for the social health insurance.

Difficulty in access to treatment intensified this participant's financial problems. She usually received hemodialysis at a private hospital although she was very poor because there was not any space available for her. The medical expenses of having treatment from the private hospital were commonly more expensive than a government hospital. To her knowledge, if she had any health problems she needed to go back to the hospital where she received the treatment. Therefore, whenever she had urgent health problems, she went to that private hospital. She had to pay a lot of money. The cost of an extra hemodialysis at night is more expensive than a regular one. Later on, a nurse advised her to go to the emergency room at the government hospital in order to gain basic supportive treatments at low cost. The next day, she would be referred for proper management. Therefore, she was able to prevent spending extra medical expenses that would temporarily reduce her financial problems. However, she still encountered and needed help from social networks. She said, "I had another friend whom I met at work. She was always concerned about my financial situation. She would ask and support me. She usually gave me canned food...My son always got a scholarship from school, not for having high scholarly performance, but for being in a poor family." Sometimes, she gained financial support from health-care personnel. She said, "Some days, the nurses at the dialysis unit paid all the treatment for me. They said they would pay for me, therefore, I could save the money for the next treatment."

The difficulties that participants dealt with in their life seemed to be hard. However, if they were motivated and saw the situation as challenges to be overcome; then they would find a way to solve their problems.

In summary, a journey from a healthy person to an end-stage renal disease patient necessitates tremendous changes in participants' lives. "A path through an unknown world" has begun since participants were diagnosed. They experience a broad range of symptoms and complications that affected their daily functioning and well-being. Many of them experienced life-threatening situations. Finally, everyone required costly regular hemodialysis for survival. Participants needed to deal with their illness under individual socio-cultural contexts of age, gender, and educational/marital/and economic status. Their lives were tied to suffering caused by a chronic illness from which they could not escape. They inevitably lived with their illness. For further understanding how Thai ESRD who were undergoing hemodialysis deal with their illness as a whole, the theoretical model depicted in Figure 1 is proposed.

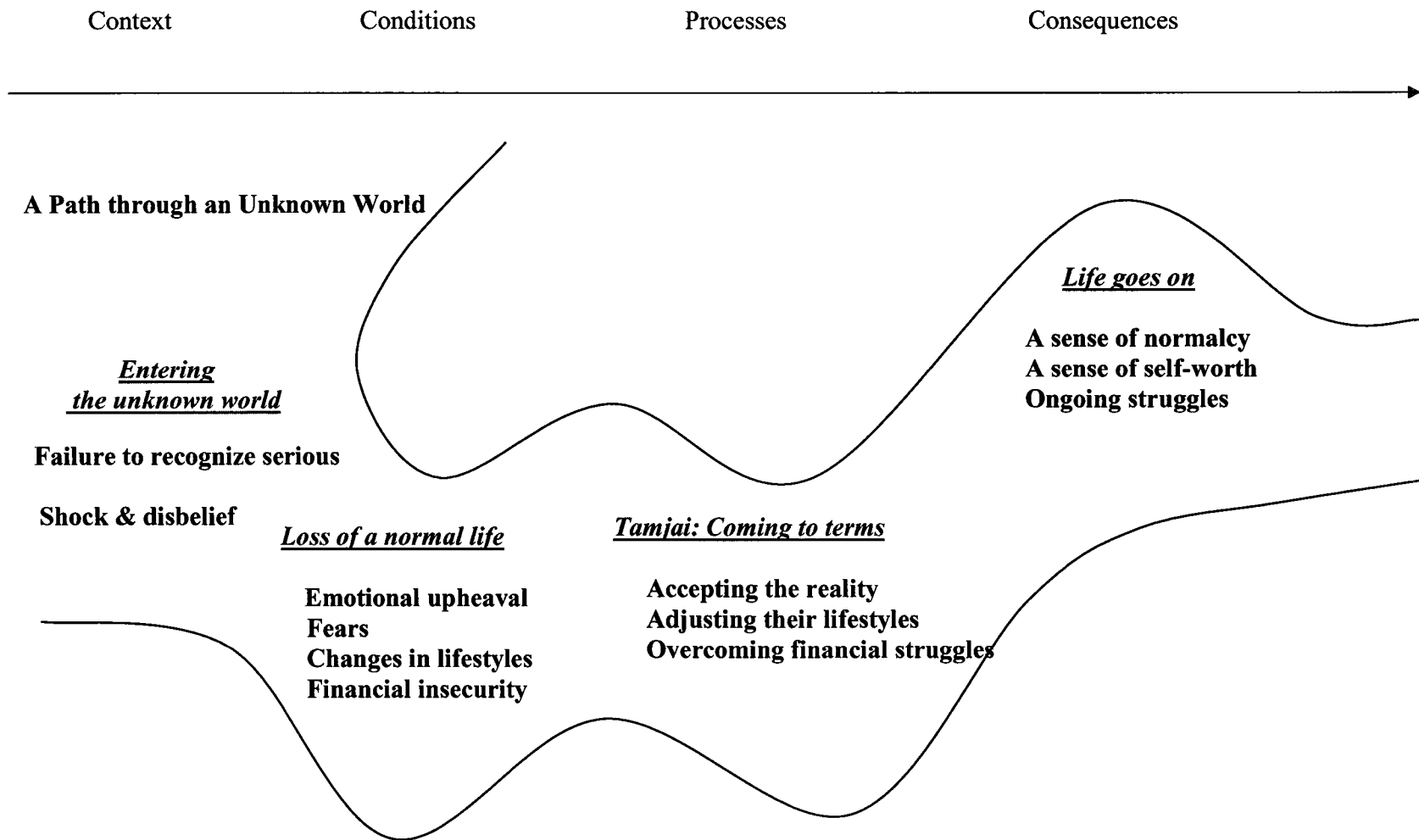


Figure 1. A path through an unknown world: A theoretical model of living with illness among Thai ESRD patients.

A Theoretical Model: A Path through an Unknown World

From the findings, a theoretical model of living with ESRD among Thai ESRD patients was developed using grounded theory. The theoretical model is the relationship of social interaction with their conditions and consequences. The name of this theoretical model, “a path through an unknown world”, reflects the salient perspective of Thai ESRD patients who were undergoing hemodialysis. They felt like they had entered and were traveling through an unknown path.

A path is an analogy of the course of ESRD, which includes signs, symptoms, complications, treatment modalities and so on. Being sick as ESRD patients and having to walk this path, they did not know what was going to happen to their lives. The situation of being sick was like entering an unknown world. The findings revealed it is an unknown world because participants failed to recognize symptoms as an antecedent to ESRD. They were shocked at the ESRD diagnosis and could not believe what was happening to them.

This path is not a straight path (see Figure 1). The entry of the path pointed downward at the beginning reflects the deteriorated health of the participants that need to start hemodialysis treatments to survive. The wavy line reflects the fluctuations of the symptoms and the unstable conditions of ESRD. The direction of this wavy line moves up and down, which reflects their condition as they walk along the path. The participants experienced some relief of symptoms after hemodialysis treatment, but they also sometimes experienced some exacerbations of the symptoms and discomfort.

This path started out wider and became narrower as the participants went through. The narrower trend means that the unknown part is getting smaller. The participants have learned about ESRD, the treatments, and managements of their illness. Within the context of “entering

the unknown world”, their health condition changed and affected “loss of a normal life”. The process of coping and dealing with the loss of their normal life is called “Tamjai: Coming to terms”. It refers to how participants have learned to live with their illness. Along the path, the theme “Life goes on” emerged as the consequence of their coping processes.

According to grounded theory, a theoretical model describes a process of social interaction: action and interaction between the context and conditions that influence and contribute to processes and consequences. Each component in this theoretical model is woven and affected by each other without any boundary.

Chapter V

Discussion of Findings

This chapter includes the discussion of the findings, a path through an unknown world, in details as well as in relationship to selected theories and previous research.

Entering an Unknown World

The primary causes of becoming an ESRD patient usually are diabetes, hypertension, and renal disease. The participants in this study shared similar causes. In the United States, major leading causes of ESRD in 111,000 patients were patients were diabetes (44.0%), hypertension (27.6%) and other renal diseases (USRDS, 2009). In this study, diabetes and hypertension were major predisposing causes of ESRD. Many participants were not aware that ESRD could be a complication of their chronic illnesses. Some participants were not aware of any underlying health problems. A unique finding from this study was that many of the participants reported that they were healthy people before they were diagnosed with ESRD. The insufficient health knowledge and unhealthy lifestyle practices resulted in being ESRD patients. The lack of awareness and knowledge led to lateness in seeking medical treatment. Many participants had limited choices by the time they got medical attention. They usually needed to receive hemodialysis treatment immediately.

The sudden onset of their illnesses and progression of disease were relatively rapid. The participants expressed that they did not know how the disease progressed and what the consequences of the ESRD were. The unpredictability of the disease course and its complications were major contributing factors that created an unknown world for these participants. Illness trajectory and how it changed their lives and activities of daily

living were also unknown. The reactions to the diagnosis were shock and disbelief. The findings in this study were similar to other studies exploring chronic illness and crisis theory (Charmaz, 1991; Curtin et al., 2002). The progression of ESRD requires immediate and continuous response in order to survive such that participants perceived their illness as intrusive event in life.

Participants reacted similarly to those subjects in previous studies in the literature. They were in shock and disbelief that they had the illnesses. However, the explanation underlying the shock and disbelief in participants, is different. Participants who reacted this way were those who were primarily low-educated, low income, and lived in rural areas with medical treatment that was not accessible. People in the rural area with difficulty accessing hospitals, which provide similar treatment to those from western countries, use old traditional treatments. They might see healers or use alternative medicine to treat illness or alleviate undesirable symptoms.

In the Western countries or among participants who lived in a city with higher education levels, people are more familiar with health information and Western treatment modalities. They have easier access to medical care than those who live in the rural area. Participants with low education levels, who were poor, and lived in the rural area, failed to recognize their illness.

Loss of a Normal Life

The participants held a salient perspective, which they called the “loss of a normal life” for what had happened in their lives after being diagnosed with ESRD. This finding was quite similar to several studies (Curtin et al., 2002; Charmaz, 1990; Kaba et al., 2007; Nagle, 1998). Chronically ill patients experienced their illness as an interruption,

intrusive illness, and immersion in illness (Charmaz, 1991). Similarly, ESRD patients viewed their experience as life constraints and limitations. Life depended on technology and the need to endure treatment (Curtin et al., 2002; Nagle, 1998). In addition, many studies indicated that participants viewed the illness and treatment as interfering with their normal life and reported negative responses to both illness and treatment. Patients became dependent as their health deteriorated over time (Cohen, 1995; White & Grenyer, 1999). Hagren, Pettersen, Serverinsson, Lutzen and Clyne (2001) also found loss of freedom, dependence on caregivers, and disrupted marital, family, and social life as sub-themes of their study. However, in this study there was no finding of a disrupted marital or family status. The participants felt “loss of a normal life” because there are many changes required while undergoing hemodialysis.

For instance, patients, who are undergoing hemodialysis, have to adhere to the regular treatments, the dietary and fluid restrictions, and the medical regimens. The findings from this study reflected the challenges that participants faced when they lost normalcy in their lives. The loss of a normal life has sub-themes of emotional upheaval, fear, changes in lifestyles, and financial insecurity. Participants in this study attended hemodialysis two to three times a week. Each entire treatment session ranged from four to five hours. In addition to mandatory and time-consuming treatments, the participants who lived far away from the hospital also added more time required for traveling. Participants’ experiences were similar to prior study (Clarkson & Robinson, 2010; Curtin et al., 2002). In Clarkson and Robinson’s study, they also found that participants lacked knowledge of their treatment regimens, limited lifestyle, faced body/mind/spirit challenges, and came up with new coping strategies.

Financial insecurity

Generally, ESRD is a major health concern worldwide with tremendous cost. In 2007, total ESRD spending in the United States was an estimated \$23.9 billion dollars, an increase of 2.6% from the previous year. An average expenditure was \$70,000 per individuals per year (USRDS, 2009). In Thailand, the cost of hemodialysis is about 400,000 baht (US \$12,100) per year. In 2008, 2.5 billion baht (US \$76 million) of the total annual National Health Security Office Budget of 120 billion baht (\$3.62 billion) has been allocated to renal replacement therapy that expanded healthcare coverage for the poor in Thailand. The cost of treatment is still a burden for the individuals and the government.

The national gross income of Thai people is \$2,200 per household per year while the cost of hemodialysis is approximately 1,500 to 2,000 baht per visit. A few participants used to pay 3,000 baht per visit by themselves when they first started hemodialysis. The cost of the treatment varies among the dialysis unit in government hospitals, private hospitals, and non-profit organizations. The findings from this study showed that the most concerning issue facing ESRD patients was finances.

There are many costs attached to hemodialysis. The direct cost is the cost of the dialysis treatment itself. The indirect cost includes the travel, time lost from work, and family or spousal support costs such as, lost work, and travel. In addition to the cost of the treatment, other expenses related to illness also had an impact on participants and their families. The feeling of financial insecurity was an ongoing issue. The level of financial insecurity varied among the participants in this study. However, all the participants did share their concerns in regard to the cost of the treatment.

The funds for hemodialysis varied among the participants. The participants could be divided into three groups depending on their sources of funds. Some participants received full financial support free of charges from the benefit of government employees. Some participants received a partial payment from social security insurance. The last group was the participants who had to pay in full for the treatment.

The first group includes the patient who is eligible for full financial support from the government and states enterprise. The benefit is from being a government and states enterprise employee. The benefit extends to the employee's spouse and parents. The second group are participants under the social security insurance scheme based on their past working status and contribution to the plan. They were allowed only limited treatments in certain facilities. The plan might approve for two treatments per week with a fixed payment of 1,500 baht per visit. If the participants required more treatments or received hemodialysis where the price was higher, they would have to pay the rest of the cost by themselves. The waiting list in the preferred facilities might be long. With less availability of government hospitals, participants had to go to private hospitals and pay the differences in the cost of the treatment themselves. The last group of participants tried to pay in full out of their pocket. They would find the funds from their savings, salary, family, and friends to pay for the treatment.

These sources of funding created financial insecurity among the participants. The healthcare system in Thailand is different from other countries in the literature. These three different sources of funds affect the process of coping with the illnesses.

Tamjai: Coming to terms

The participants gradually accepted their illness after they had received treatment for while. They learned the necessity of hemodialysis. How participants dealt with their sickness situation is congruent with the concept of coping with chronic illness. Lazarus & Folkman (1984) defined coping as “cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141). The term coping is reflective of a broad adaptive orientation that is associated with outcomes of physical and mental health, environmental mastery, and quality of life. Therefore, coping capacity referred to the ability to reduce life stresses, regulate distress and negative emotions, and gain control of one’s immediate environment. Dealing with bio-psychosocial consequences of the illness, participants dealt with symptoms, discomforts, treatment protocols, and the unpredictability of the illness trajectory, and treatment complications. Coping capacity is very important for participants in order to survive under their dynamic situation (Clarkson & Robinson, 2010; Mok, Lai & Zhang, 2004). Participants in this study tried to maintain some sort of emotional mastery and sense of self and to readjust individual roles.

The findings are similar to a model of adaptive tasks and methods of coping with chronic illness and disability defined by Moos and Holahan (2007). The conceptual model of the determinations of health-related outcome of chronic illness and disability includes five sets of factors: personal resources (Panel I); health-related factors (Panel II); social and physical contexts (Panel III); cognitive appraisal (Panel IV); adaptive tasks (Panel V); coping skills (Panel VI); and health-related outcomes (Panel VII). In this model, three set of factors (Panel I to Panel III) influence cognitive appraisal (Panel IV),

and then cognitive appraisal helps to indicate adaptive tasks (Panel IV). Panel I through Panel V mediate coping skills that finally lead to the health-related outcomes (Panel VII).

This study did not aim to evaluate the quality of life or health-related outcomes, but focused on how participants experienced their illness. The experiences of the participants in this study partially matched the model of adaptive tasks and methods of coping with chronic illness and disability by Moos and Holahan (2007). The participants had adapted or coped with the illness. The cognitive appraisal and adaptive tasks were based on the uniqueness of each participant including demographic characteristics, intellectual ability, self-confidence, personality traits, and religious beliefs. In this study, all the participants were Buddhists. The Buddhist teachings and other personal resources influenced how the illness situation was appraised. The participants developed coping skills and adapted to living with ESRD.

The distinct findings from this study are the “*tamjai*: coming to terms”. After appraising the situation, the participants accepted the illness that they have to live with. One of the major beliefs in Buddhism is karma that influences “*tamjai*”. Karma is described as an immense system of causes and effects, in which everything is related and connected to one another in some way. In the Buddhist perspective, all existing things are directly or indirectly related to the flow of causes and effects. It is believed that present experiences are caused by past actions as noted in an excerpt from prayer, “All living beings are the owner of their actions, heir to their actions, born of their actions, related to their actions, live dependent on their actions,…” Therefore, the participants accepted that the illness was their Karma and that nothing they could do to change that, except to

accept it. They found meaning in their illness and then moved on to “accepting the reality”.

Accepting Reality

According to experiences regarding threat to life, participants acknowledged that their chronic health condition, required treatment, and overall circumstances could not be changed. In many qualitative studies, ESRD patients identified treatment as a “lifeline” and “coming to terms with loss and limitations” (Nagle, 1998) or “accept it as part of life”(Al-Arabi,2006). In this present study, participants finally accepted their illness and admitted to their illness and consciously viewed hemodialysis is as mandatory treatment. One participant stated, “If there was no dialysis machine, what could I do with my life? I had never known that there was a machine functioning as the kidney before, until I was sick myself. It is a magic machine. I survived and was better after the treatments.” Many participants experienced feeling better and more comfortable with the hemodialysis.

“*Tamjai*: coming to terms” is interchangeable with accepting reality. Thai people always used the term to describe their state of mind in dealing with a difficult situation in life. Using the term “*tamjai*” has a meaning of acceptance and living within that ongoing situation. It is a common expression and value of the Thais, which based on Buddhist teachings. The principal Buddhist teaching is that nothing is permanent. The participants had been exposed to this concept because it is embedded in Thai culture, religion, and way of life. As one participant stated, “I realized the fact that I was sick, and I accepted it. People said that I might die when I first got sick. Some of them have already passed away, you know, many of them. I realize that everybody would die anyway and I am aware of this fact. Therefore, I stopped thinking too much about dying. I should live a

meaningful life. I will do my best for the rest of my life.” With this concept in mind, the participants moved on to cope with their illness which fits with adaptive tasks and coping skills in Moos and Holahan’s model (2007). The difference is the force for the coping process among the participants was from spiritual belief and the support from family and loved ones.

Nurturing Spiritual Health

Participants in this study expressed how nurturing spiritual health was the main key in dealing with the illness from the beginning and throughout their ongoing struggles. Thais believe that if one does good things for oneself as well as for others, follows the Buddha’ teachings and offers support to Buddhist monks, surely one will obtain good fortune and good health. Because of the belief in karma, the participants accepted the sickness and found ways to deal with the illness by trying to do good things like giving food to the monks and being generous to others. The idea is to gain the merit in order to upset the bad karma.

Spiritual health and religious beliefs are also reported from other studies (Carson & Koenig, 2008; Walton, 2002). The importance of religion and spirituality in dealing with illnesses is well documented in the literature. A review of quantitative studies found that religion influenced mental and physical health (Carson & Koenig, 2008). Carson and Koenig further concluded, “Religion helps people to cope with illness through a number of plausible psychological and social mechanisms, and is related to less depression, less anxiety, and fewer emotional problems, and is associated with more positive emotions, such as hope, optimism and well-being” (Carson & Koenig, 2008, pp. 56). In a study of ESRD patients in the northwestern United States, spirituality was described as a life

giving force from within, full of awe, wonder, and solitude that inspires a person to strive for balance in one's life (Walton, 2002). Nurturing spiritual health benefited participants in this study in various ways, such as decreased use of sleeping pills, less anxiety and depression, and living a meaningful life.

A number of studies exploring chronic illness have shown that people with chronic illness experienced negative feelings. Emotional responses to illness of participants in this study, for example, fear, denial, guilt, anxiety, depression, and irritation. Those were similar to other studies (Al-Arabi, 2006; Charmaz, 1991; Cohen, 1995). The participants in this study; however, fear of the unknown was more prominent than in other studies. This could be from lower educational level or the lack of knowledge about the ESRD. In addition, participants reported the severity of emotional upheaval associated with the nature of the disease itself due to an increase of waste product in their body. This particular experience is different from other chronic illnesses.

It is said that Buddhism is embedded in Thai's ways of life; however, some of the participants said that they never paid closely attention to religious practices until they were ill. They realized that they needed emotional and spiritual support from their families and religious practices when they were sick. It is less likely that they would seek emotional support from mental health professional. The participants in this study found the benefit of religious practices in nurturing spiritual health.

Seeking Care and Support

One of the coping skills that the participants in this study adopted was "seeking care and support". Seeking care was an action that participants directly dealt with their problems. Family members were the primary source of support for all participants in this

study. Thai people have strong sense of family connection. The Thai family value is that children would pay back to their parents for the difficulties that the parents face when they raise children. The pay back is an expected value of the children. However, some participants in this study were unable to pay back by taking care of their parents because of their illness. They expressed negative feeling of being a burden to their family although they were adult. The extended family in Thai society played an important role in participants' lives directly and indirectly. The whole family provided support in different ways. For instance, the son-in-law of the participant gave her a ride every time she had to go to the dialysis unit. One of the participants took a bus to dialysis by himself, but his niece would bring him some lunch during the treatment. This finding is congruent with one category of eight coping skills identified by Moos and Holahan (2007). Similar to a study by Mok, Lai & Zhang (2004), family and cultural factors affected how patients coped with their illness. In addition, the need for social support and its impact on participants' lives is congruent with many studies (Kaba et al., 2007; Mok, Lai, & Zhang, 2004; Rassmeapong, 1996). Kaba et al. indicated that social support was also associated with adherence to treatment. However, the findings from this study did not show any association between support and treatment adherence.

An important finding from this study is the strong effect and necessity of family support to the participants' coping and coming to terms with the illness. Apart from families, the participants gained support from various sources such as friends, neighbors, and colleagues. This support influenced participants' lives in different ways. They needed support for physical and psychological conditions. Finance was a major concern as previously mentioned. Many participants survived by the financial support from not only

their intermediate family, but also relatives and friends. One participant reported that the healthcare providers occasionally helped her with the payment. In the United States, this kind of behavior is considered unprofessional. However, it is more acceptable in Thailand because of the value of generosity and giving that is embedded in the Thai culture.

Buddhism has a prayer that wishes happiness and less suffering for others “May all living beings look after themselves with ease. May all living beings be free from all stress and pain.” The culture and religious belief makes the act of healthcare provider more appropriate and acceptable rather than nonprofessional.

Adjusting Dietary and Fluid Intake

Fluid intake and dietary restrictions for ESRD patients include limiting protein, sodium, phosphorous, and potassium intake. Generally, patients are limited in eating meat, salty food, nuts, vegetables, and fruits because these types of food cause excess waste products, sodium, phosphorous, and potassium. A typical Thai diet includes fresh fruits and vegetables, which could potentially be in conflict with the ESRD diet restrictions.

Thailand is a tropical country. Agriculture is a major occupation of Thai people. There are four seasons in Thailand. All year round, Thai people have a variety of fresh seasonal fruits available. Eating fruits creates a fresh and cool feeling for the Thai people who live in hot weather, where an average temperature is approximately 37° to 47° Celsius. The common diet regimen for ESRD patients, including fruit restrictions and water limitations, contradicts the typical Thai lifestyle. For instance, bananas, a high potassium fruit, is a typical fruit for everyone, particularly those who live in rural areas. Thai people usually plant bananas in their backyards because every part of a banana tree

is a source of food. Young green bananas, flowers, and the inner part of the trunk are cooked as vegetables, while ripen ones are eaten as fruits. Dried bananas are commonly served as desert or snacks. The banana is an example of the challenges of diet restriction and changes in lifestyle with which participants had to cope.

Adjusting dietary and fluid intake among participants in this study falls into one of the coping strategies identified by Moos & Holahan (2007). This coping strategy helped participants manage their discomfort, diminish or prevent possible complications, and maintain a healthy condition. By mastering the coping skills, participants were able to go on with their lives.

Consequences: Life Goes on

“Life goes on” was the theme that participants expressed about having to live their lives despite the chronic illness and hemodialysis. How they lived their lives depended on their cultural and religious views. The Thai ESRD patients from this study tried to lead a normal life as having a sense of normalcy.

A Sense of Normalcy

The findings of the study revealed that participants tried to maintain a normal life even though they were dealing with an extraordinary life situation. They had ongoing struggles with illness and changes; however, the participants expressed either directly or indirectly that they were able to lead “normal” lives. They tried to function and to perform their duties and roles in the family and society. They contributed to their family and their loved ones. For example, they played their roles as a father or a mother of their children or at least kept the elderly parents company. Participants developed a sense of mastery over their situation. For instance, they were able to perform their basic daily

activities. Participants felt proud of this ability. A study by Lindqvist, Carlsson, and Sjoden (2000) identified theme of living with chronic illness as “wishes for independence and normalcy. They noted that there were sub-themes that indicated various cognitive strategies that chronically ill individuals utilized for normalization. In this study, cognitively, many participants appreciated having survived critical conditions. They saw it as having an opportunity to live their normal life. In addition, many participants expressed their hope to be a kidney recipient. They saw that renal transplantation was the permanent solution to ESRD, not the hemodialysis. Therefore, the kidney transplant reflected the wish to be normal again.

A Sense of Self-worth

Dealing with ESRD had a great impact on participants. The impact affected their sense of self, physical changes, role switching, and psychological means. After going through hemodialysis for a lengthy period, participants gradually developed and utilized their coping strategies. One of the results of their coping was the ability to attain a sense of self-worth. Some participants developed closer relationships with family members. Some participants appreciated both good and bad things that had happened in their lives. A few participants developed new skills by learning to adjust to the changes of lifestyle, dietary restriction, and other changes with pride. Many participants attained a sense of self-worth because of their appreciation of their family's devotion. The findings in this study are consistent with previous studies that indicated the changes in personality or restructuring self and restructuring illness (Kaba et al., 2007; Curtin et al., 2002). The other way that the participants found helpful was looking at a positive domain in their lives and sharing information with those in a similar situation. They learned that their

experiences were not unusual for ESRD patients and families. In addition, when they compared themselves with others who had a more severe condition, they felt fortunate. That is another coping strategy that helped participants develop a positive sense of self from living and dealing with the illness.

Ongoing Struggles

The path to the unknown world continues. It is a long path because of the chronic condition of ESRD. Participants continued facing deteriorating health, the fluctuation of the symptoms, the unpredictability of the course of the illness and complications, the regular treatment schedule, the dietary and fluid restrictions, the changes in activities and lifestyle, and financial insecurity. As a result of the incurable disease, participants felt vulnerable. There is a sense of ongoing struggle as participants continue to walk along this path. The ongoing problems were also reported from other studies (Curtin et al., 2002; Landry, (2000); Lindqvist, Carlsson, & Sjoden, 2000).

In summary, living with ESRD starts from being diagnosed as an ESRD patient. Participants in this study had to deal and cope with dynamic problems. Participants were not alone in this circumstance; their spouses, families, and friends witnessed their struggles. The social networks, healthcare system, financial circumstances, and religious beliefs, as well as illness trajectory, influenced and shaped their situation.

Chapter VI

Critique and Implications of the Study

This study identified the processes of living with ESRD as experienced by Thai ESRD patients who were undergoing hemodialysis. With cultural perspectives and religious views, the findings of this study provided a comprehensive and culturally sensitive basis for understanding how Thai ESRD patients dealt with their illness. These findings added to the body of knowledge of the Thai population experiencing chronic illness.

Critique of the Study

Due to the limited literature on cultural aspects in this population, this study serves as a primary qualitative study in Thai ESRD patients. Among the limited research on this population, most of the studies used quantitative approaches. In addition, translation and back translation to unify the findings was also a strength that provided understanding in two languages. The diversity of the sample selection of this study included a variety of educational backgrounds, economic circumstances, and living situations. Receiving care from government or private units as well as the trajectory of illness from a group of new patients to the ones who have survived more than ten years, enhanced the diversity of the participants. Overall, the findings gave insight into how the participants were dealing with the illness and the limitations of the health care system in Thailand.

As with all qualitative research, the findings may not be applicable and transferable beyond this group. Another limitation might occur due to using a digital recorder. Some participants expressed body language that might be associated with feeling uncomfortable. This might inhibit free expression. However, only one participant declined being recorded during the interview, but allowed the researcher to take notes. Moreover, ESRD is a chronic illness with a

long trajectory, but the researcher was limited to conducting a single interview at a particular point in time. A longitudinal study with varying interview points might be beneficial. However, this study included participants at varying points along the illness trajectory.

Finally, this study focused only on participants who were receiving hemodialysis. It is unknown how many Thai ESRD patients are unable to access care. These issues should be considered for further research to understand this population as a whole.

Implications of the Study

The goal of grounded theory is to generate substantive theory. The findings can provide powerful implications for further research, nursing practices, and health policy.

Research and Theory Development

The findings from this study provide a basic knowledge of the experiences of Thai ESRD patients who are undergoing hemodialysis. Further steps should include theory testing. A qualitative study into the experiences of other treatment groups, such as peritoneal dialysis and kidney transplantation is necessary. The reason underneath the treatment options may reveal social, political, and economic inequities that may decrease opportunities for access to care. In order to understand the process of transition to being end-stage renal disease patients, research should be conducted with another group undergoing different treatment. The lived experiences may provide a bigger picture of ESRD patients as a whole. As a result, the findings may lead to nursing and health care interventions that provide unique care and facilitate living with end-stage renal disease. The developed theory should be used as an explanatory model for essential intervention in order to provide holistic care for this population. It would be interesting to explore whether the experiences of another population differ with different treatments such as peritoneal dialysis or transplantation patients as well as patients suffering from other illnesses.

Additionally, the views of ESRD patients regarding the educational program they received should be considered for further investigation. Perspectives of family members, spouses, children, or caregivers should be explored. Effectiveness of specific interventions such as educational programs in nutrition, adjusting lifestyles, and social support should be other areas of concerns. In summary, knowledge gained from this research may improve holistic care of healthcare providers for this population. Providing necessary information for successful living with the illness is another concern. Patient outcomes and ability to adhere to treatment regimens over time could be positively affected.

Nursing Practice

The findings from this study provide nurses with an opportunity to learn more about the experiences of ESRD patients. The participants of this study did not have enough self-care capacity and knowledge to anticipate any symptoms or complications of their primary chronic illness that led them to become renal failure patients. A primary goal of healthcare personnel is to prevent patients from entering end-stage renal failure. Prevention programs need to focus on individual patients and their families as well as community-based groups. Educational outreach through media, schools, and temples would increase public awareness of the disease and its consequences. As a result, patients and their families may not suffer from this catastrophic disease. Preventing patients from developing ESRD will decrease the load on a heavily impacted healthcare system. Finally, the budget for this mandatory and expensive treatment could be substituted for programs promoting a healthy lifestyle, which in turn will lower the prevalence of the illness.

The findings from these ESRD patients' voices help nurses to understand and provide appropriate care for patients. To provide support and education, nurses should be aware of the

individual difference in the transition to chronic illness. In Thai society, patients normally show respect to healthcare personnel or authority by listening, being obedient, following the suggestions, and refraining from objections. If nurses are not aware of such patients' behaviors, they may misinterpret their responses. Therefore, nurses should establish trustworthiness and provide opportunities for the patients to express their feelings with an open mind and kindly rapport when necessary. With an understanding atmosphere, patients are more likely to share or express their feelings. Therefore, nurses would gain an insight to the actual problems. With such an insight, the nurses would be able to cooperate with patients and their families to set up realistic goals for the individuals to live with their illness.

From observing other ESRD patients, the participants received indirect support and felt motivated to live with their illness. Therefore, the dialysis unit should provide facilities for social interaction among patients. Health educational programs should be provided for both patients and caregivers based upon the individuals' needs. In addition to providing educational programs for patients, constructing support groups could assist both patients and families. Nurses can enhance group meetings by providing activities that facilitate learning from one another as well as promoting healthy lifestyles compromised by the illness among patients. Constructing a support group can help them to learn more about their illness and share their feelings with patients who previously experienced a similar situation. This would be an ideal social support system. In addition, including caregivers into the group meeting may be beneficial for both caregivers and patients. For example, patients and caregivers will have opportunities to share challenges and strategies for dealing with struggles. Simultaneously, nurses can provide sources of knowledge and additional support that benefit the group meeting and learn from them.

Policy Development

This study provides an emergent theory of the experiences of Thai patients living with ESRD. End-stage renal disease has a significant financial impact on patients and their families as well as health care budgets. The findings of this study could be used to facilitate public awareness and prevent healthy people from developing ESRD. The lesson learned from this study might also have implications for public education regarding hypertension, diabetes and other diseases that could lead to renal failure. Health policy could focus on funding and staffing initiatives to provide greater patient access to treatment. Although conducting research to improve care outcomes is necessary, few health care providers are prepared to conduct research in clinical settings. In addition, nursing staff are limited by time, excessive workloads, and lack of emphasis on disease prevention. Future health policy initiatives need to include support for advanced nursing education and development of research-based nursing care practices.

References

- Al-Arabi, S. (2006). Quality of life: Subjective descriptions of challenges to patients with end stage renal disease. *Nephrology nursing journal*, 33, 285-292.
- Bihl, M., Ferrans C., & Powers, M. (1998). Comparison of stressors and quality of life of CAPD and hemodialysis patients. *American Nephrology Nurses Association Journal*, 15, 27-37.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Caress, A. L., Luker, K. A., & Owens, R. G. (2001). A descriptive study: Meaning of illness in chronic renal disease. *Journal of Advanced Nursing*, 33, 716-27.
- Carson V. B., & Koenig H. G. (Eds.). (2008). *Spiritual dimensions of nursing practice*. West Conshohocken, PA: Templeton Foundation Press.
- Charmaz, K. (1990). "Discovering" grounded theory. *Social Science and Medicine*, 30, 1161-1172.
- Charmaz, K. (1991). *Good day, bad day: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (2003). Grounded theory: Objectivist and constructive methods. In N. K. Denzen & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (2nd ed.). (pp.249-291). Thousand Oaks, CA: Sage.
- Charuwanno, R. (2005). *The meaning of quality of life among Thai end stage renal disease patients on maintenance hemodialysis*. (Unpublished dissertation). The Catholic University of America, Washington, DC.
- Chockephichit, P. (2003). *Self-care of chronic renal failure patients undergoing hemodialysis*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.

- Choowattanapakorn, T. (1999). The social situation in Thailand: Impact on elderly people. *International Journal of Nursing Practices*, 5, 95-99.
- Choowong, J. (2002). *Quality of life of chronic renal failure patients*. Unpublished Master's Thesis, Khon Kaen University, Khon Kaen, Thailand.
- Clarkson, K. A., & Robinson, K. (2010). Life on Dialysis: A Life Experience. *Nephrology nursing journal*, 37, 29-35.
- Cohen, J. D. (1995). *The experience of living on maintenance hemodialysis for twenty years and beyond: Impact on the patient and family*. (Unpublished dissertation). Union Institute, Cincinnati, OH.
- Costello, T. (1999). *Conceptions of illness and adaptation in adults with end-stage renal disease: A partnership model of inquiry*. (Unpublished dissertation). Boston College, Boston, MA.
- Curtin, R. B., Bultman, D. C., Thomas-Hawkins, C. T., Walters, B., & Schatell, D. (2002). Hemodialysis patients' symptom experiences: Effects on physical and mental functioning. *Nephrology Nursing Journal*, 29, 562-574.
- Curtin, R. B., & Mapes, D. L. (2001). Health care management strategies of long-term dialysis survivors. *Nephrology Nursing Journal*, 28, 385-394.
- Curtin, R. B., Mapes, D., Petillo, M., & Oberley, E. (2002). Long-term dialysis survivors: A transformational experience. *Qualitative Health Research*, 12, 609-24.
- Delagarza, S. M. (2000). *The influence of attachment style on coping and adaptation in adults on hemodialysis*. Texas A&M University, College Station, TX.
- Disayavanish, C., & Disayavanish, P. (1998). Introduction to traditional treatment medicine: Its validity and future perspective. *Psychiatry and Clinical Neurosciences*, 52(Suppl.), s334-s337.

- Denzin, N. K., & Lincoln, Y. S. (Eds.). (1994). *Handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Ferrans, C. E. (1996). Development of a conceptual model of quality of life. *Scholarly inquiry for Nursing Practice: An International Journal* 10, 293-304.
- Ferrans, C. E., & Powers, M. J. (1993). Quality of life of hemodialysis patients. *American Nephrology Nurses Association Journal*, 20, 575–582.
- Gilbar, O., Or-Ham, K., & Plivazyk, N. (2005). Mental adjustment, coping strategies, and psychological distress among end-stage renal disease patients. *Journal of Psychometric Research*, 58, 471-476.
- Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1994). *Basics of grounded theory analysis: Emergence versus forcing*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Gudex, C. M. (1995). Health-related quality of life in end stage renal disease. *Quality of Life Research*, 4, 359-366.
- Hagren, B., Pettersen, I. M., Serverinsson, E., Luzen, K., & Clyne, N. (2001). The hemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing*, 34, 196-202.
- Hay, C. G. (2005). Predictors of quality of life of elderly end-stage renal disease patients: An application of Roy's model (Unpublished doctoral's dissertation). Georgia State University, Atlanta, GA.
- Heiwe, S., & Dahlgren, M. A. (2004). Living with chronic renal failure: Coping with physical activities of daily living. *Advances in Physiotherapy*, 6, 147-157.

- Jablonski, A. (2007). The multidimensional characteristics of symptoms reported by patients on hemodialysis. *Nephrology Nursing Journal*, 34, 29-37.
- Jareunsangrung, J. (1999). *Development on measuring instrument of the quality of life for end-stage renal disease in hemodialysis patients*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- Jiranantawat, T. (2010). *Health Care Coverage for Renal Replacement Therapy*. Retrieved July 5, 2010, from <http://www.nephrothai.org>
- Jittinan, A. (2002). Thailand renal replacement therapy register: 1997- 2000. *Journal Nephrology Society of Thailand*, 8, 167-179.
- Kaba, E., Ballou, P, Andrea, S. Kyritsi, E.,Gerogianni,G., Zetta, S., et al. (2007). Problems experienced by hemodialysis patients in Greece. *British Journal of Nursing*, 16, 868-872.
- Kaseamsap, W., Tangcharoensathien, V., & Mugem, S. (1999). High cost of end stage renal disease: What are the solutions? *Journal Nephrology Society of Thailand*, 15, 35-41.
- Killingworth, A., & Van Den Akker, O. (1996). The quality of life of renal dialysis patients: Trying to find the missing measurement. *International Journal of Nursing Studies*, 33, 107-120.
- Kittisuksathit, S., Sethabuth, J., Vanichakarn, S., & Kongpatanakul, S. (1995). *The quality of life of hemodialysis patients: A qualitative research*. Nakhon Pathom, Thailand: Institute of Population and Social Research, Mahidol University.
- Lazarus, R., & Folkman, S. (1994). *Stress appraisal and Coping*. New York: Springer.
- Landry, D. R, (2002). *Older women's experiences living with end stage renal disease and hemodialysis treatments: Struggling with change*. Dalhousie University, Canada.

- Lev, E. L., & Owen, S. V. (1998). A prospective study of adjustment to hemodialysis. *ANNA Journal*, 25, 495-504.
- Levin, A., Lewis, M., Mortiboy, P., Faber, S., Hare, I., Porter, E. C., et al. (1997). Multidisciplinary predialysis programs: Quantification and limitations of their impact on patient outcomes in two Canadian settings. *American Journal Kidney Disease*, 29, 533-540.
- Library of Congress. (2007). *Country Profile: Thailand*. Retrieved December 2, 2005, from <http://lcweb2.loc.gov/frd/cs/profile/Thailand.pdf>
- Limannonda, B. (1995). Family in Thailand: Beliefs and realities. *Journal of Comparative Family Studies*, 26, 67-82.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*, Beverly Hills, CA: Sage.
- Lindqvist, R., Carlsson, M., & Sjoden, P. (2000). Perceived consequences of being a renal failure patient. *Nephrology Nursing Journal* 23, 291-297.
- Maharatanaviros, W. (1999). *Quality of life of patients with end-stage renal disease on hemodialysis and continuous ambulatory peritoneal dialysis*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- McCann, K., & Boore, J. (2000). Fatigue in persons with renal failure who require maintenance hemodialysis. *Journal of Advanced Nursing*, 32, 1132-1142.
- Medline Plus Medical Encyclopedia: Dialysis. Retrieved November 2, 2005, from <http://www.nlm.nih.gov/medlineplus/ency/article/003421.htm#Definition>
- Ministry of Public Health. (2004). *Thailand health profile: A summary*. Bangkok: Yutharin Printing.
- Molholland. (1987). Traditional Thai medicine. *Hemisphere*, 33, 224-229.

- Mok, E., Lai, C., & Zhang, Z.(2004). Coping with chronic renal failure in Hong Kong. *International Journal of Nursing Studies*, 41, 205-213.
- Moos, R. H., & Holahan, C. J. (2007). Adaptive tasks and methods of coping with chronic illness and disability. In E. Martz & H. Livneh (Eds.), *Coping with chronic illness and disability* (pp. 107-128). New York: Springer.
- Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzen & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research*. (pp. 220-235). Thousand Oaks, CA: Sage.
- Mulder, N. (2000). *Inside Thai society: Religion and every day life change*. Chiang Mai, Thailand: Silkworm Books.
- Nagle, L. (1998). The meaning of technology for people with chronic renal failure. *Holistic Nursing Practice*, 12, 78-92.
- Nahas, M. E. (2000). Chronic renal failure and a uremic syndrome. In R. J. Johnson and J. Feehally (Eds.), *Comprehensive clinical nephrology*. (pp 67.1-67.10) Barcelona: Mosby.
- National Health Security Office. (2007). Thailand universal health care coverage through pluralistic approaches. Retrieved July 25, 2008, from http://www.nhso.go.th/eng/index_main.jsp
- National Institute of Diabetes Digestive and Kidney Diseases, NIH. (2003). Treatment methods for kidney failure: Hemodialysis. Retrieved January 23, 2005, from <http://kidney.niddk.nih.gov/kudiseases/pubs/pdf/hemodialysis.pdf>
- National Kidney Foundation. (2002). K/DOQI clinical practice guidelines on chronic kidney disease. *American Journal of Kidney Disease*. 39 (Suppl.), 46.

- National Kidney Foundation Kidney Disease Outcome Initiative (NKF-K/DOQI) (2006) Clinical practice guidelines on chronic kidney disease. *American Journal of Kidney Disease*. 48(Suppl.), 1.
- Payutto, P. A. (1993). *A Constitution for Living*. Bangkok, Thailand: Buddhadhamma Foundation.
- Praditpornsilpa, K. (Ed.). (2007). Thai renal replacement therapy year 2007. Retrieved July 2, 2010, from http://www.nephrothai.org/news/news.asp?type=KNOWLEDGE&news_id189
- Prearungsakul, B. (2002). *Fatigue among chronic renal failure patients receiving hemodialysis* (Unpublished master's thesis). Chiang Mai University, Chiang Mai, Thailand.
- Rangphut, P. (2000). *Self-care experiences of patients with chronic renal failure who have no peritonitis from continuous ambulatory peritoneal dialysis* (Unpublished master's thesis). Prince of Songkhla University, Songkhla, Thailand.
- Rassmeapong, S. (1996). *Stress and coping in chronic renal failure patients treated by hemodialysis* (Unpublished master's thesis). Mahidol University, Bangkok, Thailand.
- Rodsawang, P. (2001). *Self-care experiences of patients with chronic renal failure who have peritonitis from continuous ambulatory peritoneal dialysis*. (Unpublished master's thesis). Mahidol University, Bangkok, Thailand.
- Rudman, L. A., Gonzales, M. H., & Borgida, E. (1995). My transplant is my life: Compliance status as a moderator of differential susceptibility to item context effects. *Personality and Social Psychology Bulletin*, 21, 340-348.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advance in Nursing Science*, 16, 1-8.

- Sakunphanit, T. (n.d.). *Universal health care coverage through pluralistic approach: Experience from Thailand*. Retrieved June 30, 2010, from www.nhso.go.th/eng/content/uploads/files/research_pub_04.pdf
- Schwandt, T. A. (1994). Constructivist. interpretivist approaches in human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: Sage.
- Shreiber, R. S., & Stern, N. P. (Eds.). (2001). *Using grounded theory in nursing*. New York: Springer.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin, & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp.273-285). Thousand Oaks, CA: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Stern, P. N. (1994). *Eroding grounded theory*. In J. M. Morse (Ed.), *Critical issues in qualitative research methods*. (pp. 212-223). Thousand Oaks, CA: Sage.
- Tangcharoensathien, V., Teerawatananon, Y., Kaseamsup, V., & Mugem, S. (2001). The Policy analysis of renal replacement therapy for end stage renal disease patients in basic care package of universal health insurance in Thailand. *Thai medical council bulletin*, 30, 215-226.
- Thai Transplant Society. (2010). Report of Kidney Transplant in Thailand. Retrieved August 9, 2010, from http://www.transplantthai.org/data_grows.php?news_id=00001

- Thailand Renal Replacement Therapy Subcommittee. (2003). *Annual Report 2003*. Retrieved January 30, 2005, from [http:// www.nephrothai.org/trt/index.asp](http://www.nephrothai.org/trt/index.asp)
- Thailand Renal Transplantation Committee. (2003). *Thailand Renal Transplantation Registry: "Update status before the end of 2003"*. Retrieved February 3, 2004, from http://www.transplantthai.org/data_grows.php?news_id=00001
- Towse, A., Mill, A., & Tangcharoensathien, V. (2004). Learning from Thailand health reforms. *BMJ*, 325, 103-105.
- United States Renal Data System. (2003). *Annual data report: Atlas of end-stage renal disease in the United States*. National Institutes of Health, National Institute Diabetes and Digestive and Kidney Diseases. MD: Bethesda.
- United States Renal Data System. (2006). Annual data report: Atlas of *end-stage renal disease* in the United States. Retrieved December 28, 2008, from http://www.usrds.org/atlas_2006.htm
- United States Renal Data System. (2009). Annual data report: Atlas of *end stage renal disease* in the United States. Retrieved January 20, 2010, from http://www.usrds.org/2009/slides/indiv/INDEX_ESRD.HTML
- Walton, J. (2002). Finding a balance: A grounded theory study of spirituality in hemodialysis patients. *Nephrology Nursing Journal*, 29, 447-56.
- Watson, M, & Ramirez, A (1991). Psychological factors in cancer prognosis. In C. L. Cooper & M. Watson (Eds.), *Cancer and Stress: Psychological, Biological and Coping studies*. Wiley: Chichester.
- White, Y., & Grenyer, B. F. S. (1999). The bio-psychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners. *Journal of Advanced Nursing*, 30, 1312-1320.

Appendix A:
Information Sheets

Appendix A
Information Sheet
Your experiences are importance and meaningful

There is a study about patients with ESRD in Nakornsawan province, "*Experiences of Thai ESRD patient who are undergoing hemodialysis*" conducted by Ms. Chuleeporn Piyasut, a doctoral student at the University of San Diego, USA. The aim of this study is to understand Thai ESRD patients who are undergoing hemodialysis. The study has the support of the director of the hospital.

What would happen if you participate in this study?

- 1). You will be asked questions about the experiences of being diagnosed with ESRD and undergoing hemodialysis, what it is like to be a patient with ESRD, what has been changed since you became a patient, and how you deal with situations. The conversation will be tape recorded, only Ms. Chuleeporn and her researcher team will have access to this conversation.
- 2). You may be interviewed 1-2 times at your choice of times and places. The interview will last about 60-90 minutes.
- 3). Everything you tell her will be confidential between you and her, except for these two situations (a) if you tell her that you are thinking of hurting yourself, she will have to contact your dialysis unit to ask for help and an essential service for you, (b) if you have been abused, she will have to report that situation.

If you think you might be willing to be in this study, these are your choices:

You could sent this form to the staff nurses at the units or
contact Ms. Chuleeporn Piyasut at the contacted number provided below.

Important Notice

Participation in this study is voluntary; nobody can force you to participate in this study. Your decision to participate in this study will not effect your receiving health care from the hospital.

Contact Information

If you have any questions about this study, please contact:
Ms. Chuleeporn Piyasut at any time, at home (056) 227-310 or, cell (01) 914-2003,
or email cpiyasut@yahoo.com. In the United State, call (619) 886-4955

Your name _____ Contacted number _____

คำชี้แจงการวิจัย

ขณะนี้มีการศึกษาวิจัยในผู้ป่วยไตวายเรื้อรังในจังหวัดนครสวรรค์ เรื่อง

“ประสบการณ์ของผู้ป่วยโรคไตที่ได้รับการรักษาโดยการฟอกเลือดล้างไต”

โดย นางสาว ชุติพร ปิยสุทร นักศึกษาปริญญาเอก จากมหาวิทยาลัย ซาน ดิเอโก ประเทศสหรัฐอเมริกา
วัตถุประสงค์หลักในการเรียนรู้และทำความเข้าใจประสบการณ์ของคุณขณะได้รับการรักษาโดยการล้างไต
คุณจะต้องทำอะไรในการร่วมวิจัยครั้งนี้

จะมีการพูดคุยซักถามเกี่ยวกับประสบการณ์ของคุณ เมื่อทราบว่าเป็นโรคไต และขณะที่ได้รับการรักษา
โดยการล้างไตนั้น คุณรู้สึกอย่างไรหรือมีอะไรบ้างที่เปลี่ยนแปลงในชีวิตของคุณ และคุณจัดการกับการ
เปลี่ยนแปลงเหล่านั้นอย่างไร เป็นต้น การสนทนาจะบันทึกลงในเทปคลาสเซ็ท โดยที่จะเปิดเป็นความลับ
สำหรับทีมผู้ทำวิจัยเท่านั้น การพูดคุยจะกำหนดโดยคุณตามสถานที่และเวลาที่ความต้องการ ในการพูดคุยอาจใช้
เวลาประมาณ 60-90 นาที ถ้าผู้วิจัยยังได้รับข้อมูลไม่เพียงพอ คุณอาจจะได้รับการนัดหมายการพูดคุยอีกครั้ง
บทสนทนาที่คุณเล่าจะเป็นความลับระหว่างคุณและผู้วิจัยเท่านั้น ยกเว้นในกรณีดังต่อไปนี้ คือ

ก. ถ้าคุณเล่าว่าคุณมีความคิดที่จะทำร้ายตัวเอง ผู้วิจัยอาจติดต่อทางหน่วยไตเพื่อให้การช่วยเหลือคุณ
ตาม ความเหมาะสม

ข. ถ้าคุณถูกคุกคามหรือถูกทำร้าย ผู้วิจัยอาจขอความช่วยเหลือเพื่อแก้ไขสถานการณ์ดังกล่าว

ถ้าคุณมีความยินดีที่จะเข้าร่วมในการวิจัยนี้

ขอให้คุณส่งแบบฟอร์มนี้พร้อมลายเซ็นของคุณแก่พยาบาลหรือผู้วิจัยโดยตรง หรืออนุญาตให้พยาบาล
บอกรายชื่อและเบอร์โทรศัพท์เพื่อให้ผู้วิจัยการติดต่อนัดหมายเวลาในการพูดคุยกับคุณภายหลัง การเข้าร่วม
โครงการวิจัยนี้เป็นโดยการสมัครใจเท่านั้น ไม่มีใครสามารถบังคับให้คุณให้เข้าร่วมโครงการนี้ การตัดสินใจเข้า
ร่วมในการวิจัยนี้หรือไม่จะไม่มีผลใด ๆ ต่อการได้รับการดูแลจากเจ้าหน้าที่ในโรงพยาบาลทั้งสิ้น

การติดต่อผู้วิจัย

คุณสามารถสอบถามข้อสงสัยและรายละเอียดเกี่ยวกับการเข้าร่วมในการวิจัยครั้งนี้กับผู้วิจัยคือ นางสาว
ชุติพร ปิยสุทร ได้ตลอดเวลา โดยโทรที่ (056) 227-310 (บ้าน) หรือ (01) 914-2003 (มือถือ)

ชื่อ - สกุล _____ ผู้วิจัยสามารถติดต่อข้าพเจ้าได้ที่เบอร์โทรศัพท์ _____

Appendix B:
Interview Guide

Appendix B

Interview Guide

1. Tell me about your general state of health and well-being.

2. What is it like for you - having renal problems?

Probe: -How did you feel when you were diagnosed ?

-What was your major concern?

-What is your major concern now?

3. What changes have you experienced since your diagnosis?

Probe: -How would you describe yourself as an ESRD patient?

-Are there any changes in your appearance or life style?

-How would you describe a typical day in your life?

4. What is it like to be on hemodialysis?

Probe: -Did your daily life patterns change with hemodialysis?

In what way?

- How has being on dialysis affected your family relationships?

5. What are the most difficult or most challenging issues you have faced with this illness and treatment?

Probe: -How did you deal with these issues?

-Who or what are your most helpful sources of support?

6. Is there anything else that you want to tell me that we have not discussed?

Appendix C
Demographic Data Form

Appendix C

Demographic Data Form

Code Number _____

- 1) What is your age? _____
- 2) How long have you been diagnosed as an ESRD? _____
- 3) How long have you been treated with hemodialysis? _____
- 4) How often do you visit the dialysis unit? _____
- 5) What were your other problems or disease prior to ESRD? _____
- 6) Educational level
Elementary School or less _____ High School _____
Vocational education _____ University _____ other degree _____
- 7) Marital status: Single _____ Married _____ Widowed _____ Divorced _____
- 8) How many people live in your home with you? _____
- 9) What is your religion? _____
- 10) Do you receive any health care benefits? What type? _____

Appendix D
Research Participant Consent Form

Appendix D

Research Participant Consent Form

Experiences of Thai ESRD Patients who are undergoing Hemodialysis

Chuleeporn Piyasut RN is a doctoral student in nursing at the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a dissertation research project she is conducting for the purpose of exploring experiences of Thai ESRD patients who are undergoing hemodialysis.

The project will involve 1-2 interviews that ask questions about thoughts and feelings associated with undergoing hemodialysis including your demographic data. The interviews will last about 60 to 90 minutes and will be at a time and place of your choices. Participation is entirely voluntary and you can refuse to answer any questions and/or quit at any time. Should you choose to quit, no one will be upset with you and your information will be destroyed right away. If you decide to quit, nothing will change about your access to health care services and the way doctors and nurses care for you.

The information you give will be analyzed and studied in a manner that protects your identity. That means that code number will be used and that your real name will not appear on any of the study materials. All information you provided will remain confidential and locked in a file cabinet in the researcher's office for a minimum of five years before being destroyed.

There may be a risk that participating in the interview may make you feel tired. If you experience emotional distress during the interview, a referral will be provided to a mental health professional. Remember, you can stop the interview at any times if you feel tired or for any other reason.

The benefit to participating will be in knowing that you helped nurses and health care providers understand ESRD patients' experience and learn how to provide better care in the future.

If you have any questions about this research, please contact Chuleeporn Piyasut (056) 227-310 or Dr. Patricia Roth, Ed D, dissertation chairperson, at the University of San Diego at (619) 260- 4572.

I have read and understood this form, and consent to the research it describes to me.
I have received a copy of this consent form for my records.

Signature of Participant

Date

Name of Participant (Printed)

Signature of Principal Investigator

Date

Appendix D (Thai Version)

แบบฟอร์มคำยินยอมเข้าร่วมโครงการวิจัย

ประสบการณ์ของผู้ป่วยไตวายเรื้อรังที่ได้รับการรักษาโดยการล้างไต

นางสาว ชุติพร ปิยสุทธิ์ นักศึกษาระดับปริญญาเอก คณะพยาบาลศาสตร์ มหาวิทยาลัยซานดิเอโก ประเทศสหรัฐอเมริกา กำลังทำการวิจัยหัวข้อดังกล่าว เพื่อศึกษาประสบการณ์ในการได้รับการรักษาโดยวิธีการล้างไตของผู้ป่วยภายในจังหวัดนครสวรรค์ ดังนั้นคุณจึงได้รับเชิญเข้าร่วมในการวิจัยนี้

ในการวิจัยครั้งนี้คุณจะถูกสัมภาษณ์เกี่ยวกับความคิด ความรู้สึกและเล่าประสบการณ์ตั้งแต่ได้รับการรักษาโดยวิธีล้างไต รวมถึงข้อมูลพื้นฐานทั่วไปของคุณ การสัมภาษณ์นี้จะใช้เวลาประมาณ 60 ถึง 90 นาที ณ สถานที่และเวลาที่สะดวก

การเข้าร่วมโครงการนี้เป็นการสมัครใจของคุณ ดังนั้นคุณมีสิทธิที่จะปฏิเสธที่จะตอบคำถามที่คุณไม่อยากจะตอบ เลื่อน หรือยกเลิกการให้สัมภาษณ์ได้เมื่อคุณต้องการ

ถ้าคุณหยุดการให้สัมภาษณ์ ข้อมูลจะถูกทำลายโดยทันทีและคุณจะมีได้รับผลกระทบใด ๆ ทั้งสิ้น ไม่มีการเปลี่ยนแปลงใด ๆ เกี่ยวกับการได้รับบริการจากแพทย์ พยาบาลหรือเจ้าหน้าที่ต่าง ๆ

การศึกษาและวิเคราะห์ข้อมูลที่คุณให้สัมภาษณ์ จะไม่มีการระบุชื่อและนามสกุลของคุณในเอกสารทุกชนิด โดยจะมีการใช้ตัวเลขกำหนดในเอกสารเพื่อการวิเคราะห์หรือนามสมมุติสำหรับการเขียนรายงาน ผลการวิจัย ข้อมูลต่าง ๆ จะถูกเก็บรักษาเป็นความลับใ้คงอยู่เป็นระยะเวลานาน 5 ปีก่อนการทำลาย

อาจมีภาวะเสี่ยงเล็กน้อยจากการให้สัมภาษณ์นี้ บางครั้งอาจจะทำให้คุณรู้สึกอ่อนเพลียหรือรู้สึกเศร้าใจ ถ้าความรู้สึกดังกล่าวส่งผลร้ายต่อสุขภาพจิตของคุณ คุณจะได้รับการส่งต่อเพื่อการรักษาที่เหมาะสมต่อไป โปรดจำไว้ว่าคุณสามารถหยุดการให้สัมภาษณ์นี้ได้ ไม่ว่าจะด้วยเหตุผลใด ๆ ก็ตามตลอดเวลาของการให้สัมภาษณ์

ประโยชน์สำหรับการเข้าร่วมโครงการวิจัยนี้จะทำให้พยาบาลและเจ้าหน้าที่สาธารณสุขได้เรียนรู้และเข้าใจในประสบการณ์ของคุณ อันจะเป็นพื้นฐานของการพัฒนาคุณภาพในการดูแลผู้ป่วยที่ได้รับการรักษาด้วยการล้างไตในอนาคต

หากคุณมีข้อสงสัยเกี่ยวกับการศึกษาวิจัยนี้ โปรดสอบถามได้ที่ นางสาว ชุติพร ปิยสุทธิ์ โทร 0-5622-7310 (บ้าน) หรือ 08-3872-7800 (มือถือ) หรือที่ปรึกษาโครงการวิจัยนี้คือ ศาสตราจารย์ ดร. แพททรีเซีย รอท มหาวิทยาลัยซาน ดิเอโก proth@sandiego.edu, โทร 1-619-260-4572

คุณได้อ่านและเข้าใจรายละเอียดในการเข้าร่วมโครงการวิจัยนี้ ข้าพเจ้าได้รับเอกสารการเข้าร่วมโครงการวิจัยนี้ไว้เป็นหลักฐาน

.....
ลายมือชื่อ ผู้ให้สัมภาษณ์

.....
วันที่

.....
ชื่อ-นามสกุล ของผู้ให้สัมภาษณ์

.....
ลายมือชื่อ ของผู้สัมภาษณ์ (นางสาว ชุติพร ปิยสุทธิ)

.....
วันที่

Appendix E

Typist's Confidentiality Pledge

Appendix E

Typist's Confidentiality Pledge

I will be typing Chuleeporn Piyasut's notes from her transcriptions of her interviews for her dissertation research:

Experiences of Thai ESRD Patients who are undergoing Hemodialysis

I promise to hold all individuals' interviews confidential and to maintain their anonymity. I will not know the name of the informants, but if I should recognize information that enables me to identify any of the participants. I agree to maintain their anonymity and confidentiality. By signing this agreement, I pledge to keep all information strictly confidential. I will not discuss the information I have typed with any person for any reason. I understand that to violate this agreement would constitute a serious and unethical infringement on the informant's right to privacy

Signature of Typist

Date

Signature of Principal Investigator

Date

Appendix F

Translator's Confidentiality Pledge

Appendix F

Translator's Confidentiality Pledge

I will be participating in the dissertation research project entitled:

Experiences of Thai ESRD Patient who are undergoing Hemodialysis

I will read and discuss the interview transcripts to confirm accuracy of translation with the researcher. I will not know the name of the informants, but if I should recognize information that enables me to identify any of the participants. I agree to maintain their anonymity and confidentiality. By signing this agreement, I pledge to keep all information strictly confidential. I will not discuss the information I have read with any person for any reason. I understand that to violate this agreement would constitute a serious and unethical infringement on the informant's right to privacy

Signature of translator

Date

Chuleeporn Piyasut
Investigator

Date

Appendix H

Permission for Participant Recruitment from the Settings



Sawanpracharak Nakornsawan Hospital
43 Authakawee Road
Muang, Nakornsawan 60000
Thailand

2 May 2008

To Whom It May Concern:

The purpose of this letter is to offer my full support for the study entitled "Experiences of Thai End-stage renal disease (ESRD) Patients who are Undergoing Hemodialysis: A Grounded theory" conducting by Ms. Chuleeporn Piyasut. This hospital has provided dialysis treatment for ESRD patients in Nakornsawan province and other areas that closed by. Once she has obtained IRB approval from her university, and our committee reviewed the proposal of her study that is least invasive approach. Therefore, she is welcome to conduct her study at this hospital. I am aware the purpose of the study I will encourage my staffs to provide an essential assistant for the study.

I understand that this study based on voluntary participation of out- patients with ESRD whom receive hemodialysis treatment in this hospital.

If you require additional acknowledgement of my support for this study, please feel free to contact me.

Sincerely,

.....
(Chalerm Saksornchai)
(Full name) MD. Tel. 0-5621-9888

Director of Sawanpracharak hospital

Ruamphat Hospital
276 Sawanvithi Road
Muang, Nakhon Sawan 60000
Thailand

2 May 2008

To Whom It May Concern:

The purpose of this letter is to offer my full support for the study entitled “Experiences of Thai End-stage renal disease (ESRD) Patients who are Undergoing Hemodialysis: A Grounded theory” conducting by Ms. Chuleeporn Piyasut. This hospital has provided dialysis treatment for ESRD patients in Nakhon sawan province and other areas that closed by. Once she has obtained IRB approval from her university, and our committee reviewed the proposal of her study that is least invasive approach. Therefore, she is welcome to conduct her study at this hospital. I am aware the purpose of the study I will encourage my staffs to provide an essential assistant for the study.

I understand that this study based on voluntary participation of out- patients with ESRD whom receive hemodialysis treatment in this hospital.

If you require additional acknowledgement of my support for this study, please feel free to contact me.

Sincerely,

.....
(Kitti Tungbunjerdsook) MD.

Director of Ruamphat hospital

Tel. 1-66-056-223-600

Fort Chiraprawat Hospital
161 M.1 T. Nakhonsawanoak
Paholyothin Rd,
Maung, Nakhonsawan 60000
Thailand

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To Whom It May Concern:

The purpose of this letter is to offer my full support for the study entitled "Experiences of Thai ESRD Patients who are Undergoing Hemodialysis: A Grounded theory" conducting by Ms. Chuleeporn Piyasut. Fort Chiraprawat hospital has provided a dialysis unit for ESRD patients for many years. In our dialysis unit, there are one nephrologist, three registered nurses, and seven hemodialysis machines that provide treatments for patients in Nakhonsawan province and other areas that closed by. Our committee conducted a meeting to review her proposal study, and allowed her to contact the dialysis unit directly. Since she has obtained the institutional review board (IRB) approval from the University of San Diego, she is welcome to conduct her study at this hospital. I am aware the purpose of the study I will encourage my staffs to provide an essential assistant for the study.

I understand that this study is based on voluntary participation of out-patients with ESRD whom received hemodialysis treatment in this hospital.

If you require additional acknowledgement of my support for this study, please feel free to contact me.

Sincerely,



Col. Somneuk Bongkodmalee Tel. 1-66-56-255-064

Deputy Director Fort Chiraprawat Hospital

Srisawan hospital
 33/64 Dowadoun Road
 Muang, Nakhonsawan 60000
 Thailand

12 June 2008

To Whom It May Concern:

The purpose of this letter is to offer my full support for the study entitled “Experiences of Thai end-stage renal disease (ESRD) patients who are undergoing hemodialysis: A grounded theory” conducting by Ms. Chuleeporn Piyasut. This hospital has provided dialysis treatment for ESRD patients in Nakhonsawan province and other areas that closed by. Once she has obtained IRB approval from her university, and our committee reviewed the proposal of her study that is least invasive approach. Therefore, she is welcome to conduct her study at this hospital. I am aware the purpose of the study I will encourage my staffs to provide an essential assistant for the study.

I understand that this study based on voluntary participation of out-patients with ESRD whom receive hemodialysis treatment in this hospital.

If you require additional acknowledgement of my support for this study, please feel free to contact me.

Sincerely,

...../.....

(Chaovalit Wimolchalao) MD. Tel. 1-66-056-311-626

Director of Srisawan hospital

Appendix I
Recruitment Advertisement

Your experiences are important and meaningful

A dissertation research study

***"Experiences of Thai ESRD Patient who are
undergoing Hemodialysis"***

By

**A doctoral nursing student from the University of San Diego USA
She is looking for volunteer end stage renal disease patients with hemodialysis
to participate in this study**



You are invited



To share your own experiences



**You may be interviewed 1-2 times
at a place and time convenient for your.**

**The conversation will last about
60-90 minutes.**

**Easy participation
You and I
just talk**

If you are interested and want to discuss the study

**Please contact
Chuleeporn Piyasut, MS, RN**

Home (056) 227-310, cell (01) 914-2003, or email: cpiyasut@yahoo.com

or

Contact nursing staff at the dialysis unit

เรื่อง “ประสบการณ์ของผู้ป่วยที่ได้รับการรักษาโดย การ ฟอกเลือดล้างไต”

โดย นางสาว ชุติพร ปิยสุทธิ์ นักศึกษาปริญญาเอก จากมหาวิทยาลัย ซานดิเอโก ประเทศสหรัฐอเมริกา

ต้องการอาสาสมัคร ผู้ป่วยโรคไตที่ได้รับการรักษาโดยการฟอก เลือด ล้างไต



จะมีการพูดคุยซักถามเกี่ยวกับประสบการณ์ของคุณ คุณรู้สึกอย่างไร

หรือมีอะไรบ้างที่เปลี่ยนแปลงในชีวิตของคุณ และคุณจัดการกับการเปลี่ยนแปลงเหล่านั้นอย่างไร เป็นต้น



เมื่อไร



ณ วัน เวลา และสถานที่ ที่คุณสะดวก

การพูดคุยอาจใช้ประมาณ 60-90 นาที

ถ้าคุณมีความยินดีที่จะเข้าร่วมในการวิจัยนี้ คุณสามารถ ติดต่อ



นางสาว ชุติพร ปิยสุทธิ์ โทร (056) 227-310 (บ้าน) 08-3872-7800 (มือถือ)

หรือ อนุญาตให้พยาบาล บอกรายชื่อและเบอร์โทรศัพท์ของคุณเพื่อให้ผู้วิจัยติดต่อนัดหมายการพูดคุยกับคุณภายหลัง

สอบถามข้อสงสัยและรายละเอียดเกี่ยวกับการเข้าร่วมในการวิจัยครั้งนี้ได้ตลอดเวลา

ขอขอบคุณทุกท่านที่ สนับสนุนอย่างดียิ่ง